NHS
National Institute for Health Research

Clinical Research Network
Mental health

Growing a service user and carer research resource

A report of a pilot project designed to develop a local network of service user and carer researchers in mental health research

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Delivering research to make patients, and the NHS, better

Acknowledgements

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1. Executive Summary

This pilot project, funded through MHRN Flexibility and Sustainability funding, was collaboratively designed, delivered and evaluated by the MHRN, Heart of England Hub and Suresearch, a Midlands based network of mental health service users and their allies.

The project aimed to increase the numbers of service users and carers with the knowledge, skills and confidence to participate in the research activities in the Heart of England Hub by:

- Training service users and carers for an intermediate level of involvement in hub research.

- Providing a refresher course for service users and carers with some previous research experience.

- Training service users and carers for an advanced level of involvement in hub research, including being able to be a research collaborator for NIHR projects.

- Generating a profile of service user and carers' research skills and interests and agreeing plans to develop individuals' future involvement in research following course completion.

- Establishing a database of regional service user/carer researchers' interests and skills.

The project achieved its aim by delivering, and evaluating the outcomes of courses at three levels to thirty one participants. Both the project evaluation and an independent evaluation evidenced high levels of satisfaction amongst participants about what the project offered and what was achieved.

2. Introduction and Context

This report provides an account of a pilot project. The project aimed to provide research training for mental health service users and carers. It was a collaborative endeavour between the MHRN (Mental Health Research Network), Heart of England Hub **www.crn.nihr.ac.uk** and Suresearch, a Midlands based network of mental health service users and their allies.

At the time of the project the MHRN, as part of the National Institute of Health Research (NIHR), was working to make mental health research happen in the NHS in England through a coordinating centre and eight regional offices-hubs. The Heart of England Hub supported mental health research across Birmingham and the Black Country, Wolverhampton, Staffordshire, Shropshire, Coventry, Warwickshire, Worcestershire, Leicestershire and Northamptonshire. In working with those involved in research projects the Hub aimed to facilitate the meaningful involvement of past and present users of mental health services in research. It used the MHRN Menu of levels of Service User Involvement to identify the range of ways service users and carers can engage.

Suresearch is a user led Midlands's network of mental health survivors, service users and their allies who have an interest in mental health research and education. Based at the Institute of Applied Social Studies, the University of Birmingham, Suresearch members share experience and/or an interest in mental health research and education. Through its network Suresearch aims to provide information, support, training and opportunities for service users and survivors to contribute their considerable expertise to mental health research and education. (www.suresearch.org.uk)

These two organisations brought differing perspectives to this pilot project. The MHRN is embedded in health service research. Suresearch exists to ensure that the experiences and expertise of people receiving mental health services are used to enhance mental health research and education. Both share a commitment to increasing the involvement of service users and carers in all aspects of mental health

research. The Service User Development Officer for the Heart of England Hub is a member of, and a regular contributor to, Suresearch's monthly network meetings.

This report provides an account of the development of the project, what it achieved and a reflection on what can be learnt from it by those interested in increasing mental health service user and carer involvement mental health research.

3. The project

A) Vision

The vision for the project was to grow a resource of service users and carers who could contribute their expertise to mental health research in the region. It was envisaged that such a resource could then be used to improve the quantity and level of service user involvement in NIHR (National Institute of Health Research) projects in the Heart of England Hub. At the same time it could contribute to the sustainability of the research workforce through equipping service users and carers to become actively involved in mental health research.

B) Preparation and Development

The project was designed by a small group of Suresearch members and MHRN staff. It secured MHRN Flexibility and Sustainability Funding in the summer of 2010 and was completed in October 2012.

Its overall objective was to achieve an increase in the numbers of service users and carers with the knowledge, skills and confidence to participate in research in relation to the MHRN Heart of England Hub and Faculty members by,

- Training approximately 12 service users and carers for an intermediate level of involvement in hub portfolio research activity.
- Providing a two session refresher course for service users and carers with some previous research experience who were contemplating completing applications for an advanced research course.

- Training approximately 12 service users and carers for an advanced level of involvement in hub portfolio research activity, including being able to be a research collaborator for NIHR projects.
- Generating a profile of participants' research skills and interests and agreeing a plan for each participant to develop their involvement in mental health research following course completion.
- Establishing a database of regional service user/carer researchers with their interests and skills.

A steering group comprising the MHRN's Regional Office Manager, Service User Development Officer, Social Care Lead and five Suresearch members took on the role of shaping, delivering and reflecting on the project. Their first step was to appoint a part time research project coordinator whose role was to undertake overall responsibility for managing the initial setup, the delivery and the evaluation of the training package. The research project coordinator met with the steering group at regular intervals throughout the project. Members of the steering group also provided mentoring and direction to those participating in the project as required.

In its formative discussions the group focussed on:

- Ensuring that the three courses designed and delivered by the project, engaged with the wide spectrum of knowledge about research that exists amongst mental health service users and carers with an interest in research. This ranges from those with no previous experience of research training to individuals with first and higher degrees in which research training had been a component.
- Ensuring that a research placement was incorporated in the advanced course. The rationale behind this decision was to ensure the course participants were afforded an opportunity to practice some of the research skills they had acquired on the course within a safe and supportive environment.
- Ensuring that each course met the appropriate level of the MHRN's Service User Involvement Menu (**www.crn.nihr.ac.uk**).

- Ensuring that a substantial amount of individual support and mentoring was provided to participants. The experience of Suresearch (and other teaching and learning organisations like the Open University) suggests this kind of assistance is crucial to the achievement of adult learners who are managing mental health issues in their lives.
- Making the necessary arrangements for reasonable travel expenses, in cash, to be available on the day to reimburse participants attending open meetings and/or subsequent training courses.
- Devising a promotion and recruitment strategy that offered potential participants information about the project and the support it provided, through open meetings and meeting members of the steering group.

Recruitment to the project's courses involved distribution of invitations through the established networks of MHRN and Suresearch. The research project coordinator then followed up any expressions of interest by email and telephone and booked individuals into meetings. Individuals were then contacted the day before the meeting as a reminder.

For each course applicants had to complete a brief application form providing information about their previous training/education and interest in research. For the refresher and advanced courses more detailed information was requested from individuals.

The beginner and refresher courses were devised and delivered by Dr Jan Wallcraft, an independent mental health survivor researcher and Honorary Fellow, University of Birmingham (www.Birmingham.academia.edu/JanWallcraft). The advanced course was devised and delivered by research staff from the Heart of England Hub and the Institute of Applied Social Studies, University of Birmingham.

4. The Courses- Outlines and Evaluations

A) Getting to Grips with the Essentials of Mental Health Research

Course Content

The Beginners Course was designed to introduce individuals to mental health research through:

- outlining key concepts, theories and methodologies;
- providing course participants with the basic knowledge and skills they needed to become involved in research at the first Level of Involvement Menu;
- briefly outline critiques prevalent within the research arena, making specific reference to the impact of service user and carer input in research.

A 6-day training course was offered weekly from November 2011 – December 2011 by Dr Jan Wallcraft, an independent survivor researcher, who brought a wealth of experience and knowledge to the subject area. The course covered a variety of topics.

Course Outline

I. **Week 1:** Introduction, ground rules, discussion of mentoring
II. **Week 2:** How to find information
III. **Week 3:** How to create a research question
IV. **Week 4:** Researcher skills
V. **Week 5:** MHRN and service user involvement in large scale research
VI. **Week 6:** Data analysis and writing up a report

In week 2, course participants formed research groups. Each group was tasked with demonstrating the knowledge and skills they had acquired by developing a research proposal. This proposal was presented at the final session of the course to their peers, the course trainer and steering group members. All sessions included a

taught component delivered by the course trainer, group discussions and completion of class based exercises.

The research project coordinator and course trainer played key roles in supporting individuals at and between sessions. The steering group joined the programme at the final session and participants received certificates of completion. All sessions took place in a central venue in Birmingham city centre.

Evaluation

Fifteen people signed up for this course and twelve completed it. Overall attendance was around 90%. Non-attendances were largely due to work commitments or health related appointments. Of the three people who did not complete the course, one made no appearance despite being contacted, one person withdrew after the first session as they found it too intense and one person dropped out after three sessions because they did not find it useful.

At the end of the course, students were asked to complete an evaluation form asking for feedback on a range of questions including:

- Whether the training met their expectations, with reasons if it did not,
- Was the training useful in allowing students to discuss their research ideas?
- How they found the structure and pace of the course
- What did they most like and most dislike
- What other areas they would have liked the course to have covered

(See Appendix One ‘Evaluation Form’)

There was overwhelming agreement from the participants that the course had met their expectations. The open meeting session, organised before the course started, may have assisted here. Further the provision of a mentor for each course participant could also have been a contributory factor.

Participants’ comments were generally complimentary. The friendly atmosphere, the opportunity to meet others, the group discussions, the trainer’s knowledge and

delivery, and the information given about mental health research were all valued. Three students voiced some concerns about the volume of information and hand outs and thought that a slightly longer course might have been better.
All students indicated that they would like to be involved in mental health research in the future. (For more information see Appendix Two 'The detailed responses of participants')

B) Refreshing Your Research Knowledge

Outline

The refresher course was designed to update those individuals who already possessed research knowledge. Those interested in participating completed a pre-learning needs assessment of their research knowledge and skills. This information was utilised by Dr Jan Wallcraft to tailor the course to meet the learning needs of course participants. A 2-day training course was offered over two weeks in February 2012.

Course Outline

Week 1: introduction and review of the basics of research; starting a small scale project. This day addressed:

- **I.** What is research and why do we do it?
- **II.** Theories of knowledge that underpin mental health research
- **III.** Service user-led research – what do we know about this? Information sharing session.
- **IV.** How to create a research question
- **V.** Assessing information – how do we gather new data, e.g. questionnaires and surveys. Sharing and knowledge and experience in the group.

Week 2: developing and completing a small scale project; involvement in mainstream large scale research via the MHRN. This day comprised:

I. Brief overview of quantitative/qualitative methods of data collection – pros and cons of each- utilising mixed methods research within your research study
II. 'Good' and 'bad' interviewing techniques – examples from experience
III. Writing up and disseminating results
IV. Research ethics – practical issues for researchers – ethical approval, CRB checks, researcher contracts
V. MHRN and large scale clinical research, working with the pharmaceutical industry
VI. Service user involvement in large scale research – some examples

All sessions involved a taught component, group discussion and completion of class based exercises. The sessions were held at the University of Birmingham.

Evaluation

Attendance at Session one was 100%. One person did not attend Session Two and did not complete an evaluation or after course skills form.

In order to assist with preparation of the course, participants completed a questionnaire in which they were asked to rate the level of skill or experience in various aspects of research. The questionnaire was repeated again after the completion of the course. Average scores revealed a clear increase in confidence because of the course. After course scores were mainly between 3 and 4 on a 5 point scale, indicating potential for further growth on an advanced course. (For more details see: Appendix Three 'Pre Course Questionnaire'; Appendix Four 'Post Course Questionnaire and Appendix Five 'Graph indicating the changes in participant's pre and post skills ratings').

In addition, participants were asked to complete a feedback questionnaire similar to the one used in the earlier course. Observations included the following:

- Participants overwhelmingly said the course met their expectations.
- Participants valued the coverage of many topics, being able to request inclusion of particular topics, being reminded of how much they already knew, and the interactive aspects of the course. There were a variety of views on the amount of information offered, with three participants voicing concern about the speed or shortness of the course, and one asking for more coverage of quantitative research. One participant suggested the course could be delivered as an e-learning package.
- All participants indicated that they would like to be involved in mental health research in the future. (For more details see Appendix Six 'The detailed responses of participants').

C) The Advanced Course in Research Methods

Course Outline

This course was fifteen days long and was delivered between April and October 2012. Participants were recruited through MHRN and Suresearch networks. The programme was aimed at providing course participants with the knowledge and skills they needed to become involved in research at the last Level of the MHRN Involvement Menu (**www.crn.nihr.ac.uk**).

As part of their application to the course each participant was asked to provide an outline of a research project they would be interested in pursuing. A panel made up of three steering group members and Paul McDonald (Research & Development Manager, Birmingham and Solihull Mental Health Foundation Trust) reviewed these outlines in deciding whether applicants were suitable to be offered a place on the course. Eight individuals were recruited and each was provided with a mentor from the MHRN or Suresearch. This course comprised five elements which all participants had to complete.

Element 1

Attendance at the launch of the 2012 MHRN Scientific Meeting, Birmingham Council House.

This event was in two parts.

I. Introductions, course outline, ground rules, explanation of the mentoring input and discussion of expectations of the course;
II. A funded place at the Pre-Meeting Gathering where participants watched a presentation from members of the MHRN North London Hub who outlined the 'On Becoming' project. This project was about providing learning opportunities for service user researchers to deepen their theoretical understanding and practical experience of research in general.

Element 2

Six one day teaching sessions over a period of seven weeks, delivered by research staff from the Heart of England Hub and the Institute of Applied Social Studies, University of Birmingham this covered the following,

I. **Ethics & Research Governance**. Basic tools to allow you to understand the ethical and governance context of mental health research.

II. **Making Sense of Qualitative Data**. Exploring the background to various qualitative methodologies and reflecting on their use across a range of practical contexts. Tracing how techniques of data collection and analysis are linked together by particular ways of looking at, listening to, and thinking about, the world. Conducting analysis using a thematic approach.

III. **Designing and using Research Tools**. Measurement tools and scales in the mental health field.

IV. **Practical Interview Skills**. Focusing in a practical way on individual and focus group interviewing skills as well as an introduction to action research approaches.

V. **Quantitative Research Methods**. Features of quantitative methods and explore key methods of data collection and analysis which may be used in quantitative research. Some of the key terminology used in quantitative research will be explained and considered. Exploration of quantitative research tools.

VI. **Developing a Research Proposal**. Challenges which service users may face in translating ideas for research into a viable research project. Strategies for gaining support within the academic community and beyond. Research design.

Element 3

The completion of the procedure required by the Birmingham and Solihull Mental Health Foundation Trust (hosts to the Heart of England Hub) to gain Honorary Research Fellow recognition. This was essential for participants if they were to engage in research in NHS Trusts, go into clinical areas or have any contact with service users as agreed with their nominated research team.
The procedure involved:

I. A Criminal Records Bureau (CRB) Check

II. An Occupational Health Form/Assessment

III. An NHS Declaration Form

IV. Verification of Identity

V. Confirmation of Right to Work in the UK

VI. Work Permit (if applicable)

(For more details see Appendix Seven 'Hand out given to course participants' outlining the paperwork they needed to complete for an honorary agreement) and Appendix Eight 'Information letter given to course participants').

Element 4

A seven day placement for each participant based in a research team, within the Heart of England Hub geographical area. All placement providers were known colleagues and/or associates of the MHRN and Suresearch. Most of these sat in research and development departments or were research fellows based in local universities. All possessed an interest and experience of working collaboratively with service users and carers. These placement opportunities included:

I. shadowing research nurses whilst they were completing interviews;

II. attending steering group meetings responsible for specific research projects; completing a one day training course on undertaking qualitative analysis of transcripts utilising NVivo software.

Element 5

Homework completed by students. This comprised a revision of the research proposal they had submitted in their course application, applying what they had learnt on the course and preparation of a ten minute presentation for the Recall Day.

Element 6

A recall day for participants in October 2012 at the University of Birmingham facilitated by Dr Jan Wallcraft and attended by Thomas Kabir, (MHRN Service Users in Research National Coordinator) and members of the steering group. Each participant gave a 10 minute presentation about their revised research proposal and their learning on the course. All presentations were evaluated by a panel of the facilitator and Suresearch and MHRN members. This feedback was given to each student at the end of the day.

Evaluation

Panel Members Feedback on Course Participants Revised Research Proposals/Presentations

The panel provided both verbal and written feedback to students on their revised research proposals and presentations.

Panel member's feedback highlighted the exceptionally strong and varied presentations given by course members, the strong evidence they provided of their learning and the strong potential they displayed as researchers. The Recall Day also provided the panel with evidence of the strong peer support and learning that had developed during the course.

Feedback from Course Participants

Eight people enrolled on the course and five completed all aspects of the course before the final recall day. One person decided not to complete the procedure for

gaining honorary research status and in keeping with Trust policy completed a placement without contact with service users. One person did not complete their placement and one person completed their placement after the recall day had taken place.

Participants completed evaluation forms for each classroom session, in which they were asked to rate various aspects of the session on a Lockhart scale.

The majority of participants gave the sessions either Good or Excellent ratings**.**
(For details see Appendix Nine 'Evaluation Form" and Appendix Ten 'Graph outlining the responses of course participants').

In addition, an independent review of the research placement component of the course was commissioned by the MHRN Heart of England Hub from Dr Andrew Entwistle (External Evaluation of Advanced Training Course for Mental Health Service Users/Carers, 2013).

5. Outcomes

This pilot project achieved its stated aim of increasing the numbers of service users and carers with the knowledge, skills and confidence to participate in research in relation to the MHRN Heart of England Hub. By the end of the project's life it had delivered courses at three levels to thirty one service users and carers. Participant feedback evidenced high levels of satisfaction about what the project offered and what was achieved.

Participants from all the courses have joined the MHRN database of user and carer researchers. All those satisfactorily completing the Advanced Course have signed up to be part of an 'affiliated research group' coordinated by the Hub's Service User Development Officer. This group is providing input from user and carers perspectives on the development of local research bids. In addition several participants have continued to use their research knowledge, skills and experience by contributing to local mental health research projects that they became aware of through the project.

The two organisations involved in designing and delivering the project have valued the opportunity it offered to further their research activities and interests: both through its provision of research training to existing contacts and members and generating interest from the project's participants in generating research ideas.

In addition the Birmingham and Solihull Mental Health Foundation Trust, hosts to the MHRN Heart of England Hub, report a benefit from the project in introducing them to service user and carer researchers with ideas for future research in the field and skills to collaborate in developing local research.

6. Lessons Learnt

Reflections on what lessons were learnt from this pilot project indicate that the following were essential to its success in achieving its aims:

A COLLABORATIVE APPROACH- from the outset, i.e. when the project was being designed, service users, carers, researchers and mental health service workers were involved. This collaboration was reflected in the composition of the project steering group, the provision of mentors for those undertaking the training and decisions taken re training content and the evaluation of the project. This approach was based on existing working relationships between the two organisations involved and provided the focus and energy needed to see the project through to completion.

INVESTMENT IN PROJECT ADMINISTRATION SUPPORT- a challenge to a project of this kind is to keep it 'on track' in spite of the considerable day to day work pressures on those involved. Critical to the success of this project was the appointment of a part time research project coordinator with the sole task of delivering on the project. This meant there was a clear point of contact and information exchange for all involved in the project. The job specification for this post was clear about the value the steering group placed on applicants with experience of use, as well as work in the mental health services. This meant that the post holder was able to bring a great deal to working with potential and actual participants alongside contacts with researchers and mental health practitioners.

DRAW ON USER AND CARER RESEARCH KNOWLEDGE AND EXPERTISE- through all stages of the project there was an emphasis on the evidenced contributions that service users and carers make to mental health research. This ensured that potential and actual participants were provided with a focus on the body of work which has emerged as a result of service user and carer research **(see for example, Beresford, 2000; Beresford et al., 2005; Brown, 2010; Sweeney and Beresford et al, 2009; Taylor, et al. 2005; Wallcraft, et al 2009).** The design of the courses ensured that participants learnt directly from an established survivor researcher as well as having access to examples of service user and carer generated research.

SUPPORTING INDIVIDUALS AND CELEBRATING SUCCESS- the project was continuously focussed on building the confidence of participants. To achieve this it shared full information about each stage of the training offered and what was needed for individuals to access the courses. It offered each participant a mentor, drawn from the steering group. Participants who were new to research said they found this one to one support invaluable facing the challenges and stresses they encountered in relation to learning. Contact with mentors were experienced as encouraging participants to feel knowledgeable, clear about their capabilities and potential and enthusiastic about future involvement in research.

Participants' travel expenses were paid in cash on the day. The project also provided advice for individuals concerned about the implications of joining this programme for their entitlement to benefit income (**Scott 2012, MHRN Service Users and Carers Payments Policy, Service User and Carer Participation: Helpful Benefit Rules and Benefit Pitfalls to avoid where Payments are made by an NHS Trust).** It actively maintained contact with participants who indicated that they may not be able to attend all sessions and provided them with the information they needed to continue on the programme. The independent research report on the experiences of the Advanced Course participants provides evidence of how positively this support was experienced and how confidence developed **(Dr Andrew Entwistle External Evaluation of Advanced Training Course for Mental Health Service Users/Carers, 2013).**

Having established this basis of support for what was a challenging experience the project celebrated the success of those participants who worked hard and delivered on expectations. It provided individual and group feedback on the work undertaken and sought research placements for individuals on the advanced course to build on their interests, skills and knowledge. It provided individuals who had participated with ideas for future direction and development to build on their interest's talents and learning.

7. References

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Sweeney,A and Beresford,P. et al (2009*)* **This is Survivor Research***.* PCCS Books

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Wallcraft,J et al. (2009) **Handbook of Service User Involvement in Mental Health Research.** Wiley-Blackwell

8. Appendices

Appendix 1 – Evaluation Form

'Getting to Grips with the Essentials of Mental Health Research
31st November 2011 – 5th December 2011
Evaluation Analysis

1. **Please enter the number of sessions that you attended**

2. **Did the training course meet your expectations?**

3. **If not, please say why**

4. **What did you like about the training course?**

5. **What didn't you like about the training course?**

6. **Are you interested in becoming involved in mental health research in the future?**

7. **If not please say why**

8. **Any other comments**

Service user / Carer (please circle)

Please return the completed form to HeartofEnglandHub@bsmhft.nhs.uk or post it to Sonia Minteh, MHRN, HoE Hub, Radclyffe House, 66-68 Hagley Rd, B16 8PF.

Thank you

Appendix 2 – Getting to Grips - Raw Data

1. Please enter the number of sessions that you attended

Attended all sessions - 6
Attended five sessions - 4
Attended four sessions - 2

2. Did the training meet your expectations and objectives?

Yes - 8
Very much so - 1
It exceeded them -1
I came with an open mind but found all the paperwork overwhelming - 1
I was not sure what to expect - 1

3. If not please say why?

Left blank - 11
Not applicable - 1

4. What did you like about the training course?

Group discussions – 3
New skills - 1
Trainer knowledge and style of delivery - 4
Meeting new people - 3
Atmosphere - 2
Learning from each other - 2
Everything - 1
Listening to each other/sharing experiences - 3
Academic challenge - 1
Finding out about research and realising it is something I can do - 2

5. What didn't you like about the training course?

Nothing - 3
Left blank - 1
Not applicable - 1
Too many hand outs - 1
The course was not long enough - 1
Sometimes people left out of the discussion - 1
Over talking of each other - 1
Sometimes pace was too fast - 2
Presentation notes to be handed out before start of session in order for you to be able to add your own notes - 1
Left blank - 1
Not applicable - 1

6. **Are you interested in becoming involved in mental health research in the future?**

Yes - 11
Yes - 1 (with the added comment “providing I do not have a large workload at the time of opportunity)
No -none

7. **Any other comments**

Left blank – 1
Thoroughly enjoyed it - 1
Enjoy course found it very informative and added to my knowledge base. Found Jan a good lecturer - 1
I would heartily recommend this course to anyone - 1
I think the course was suitable to the people who attended it and achieved the aim that you set it up for - 1
I do hope to further my interest in mental health research - 1
I thoroughly enjoyed all of the course and getting involved in research. It’s so good to know that I can use my personal experience to help make changes.
Thank you - 1
Many thanks - 1
I would like to be involved in future with s user and MHRN - 1
Would like to be self-employed and more empowered - 1
Time spent informing more about work of MHRN would have been more useful at the start - 1

8. **Service user / Carer**

Service user - 6
Service user & carer - 4
Carer - 1
Left blank - 1

Appendix 3 - Pre-Course Questionnaire

Training Needs Assessment

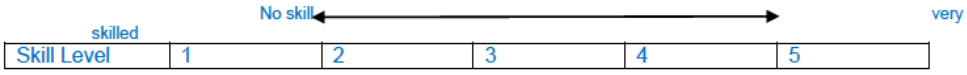
Developing Service User and Carer Research Skills

December 2011

Please read the enclosed synopsis of the **'Getting to Grips with the Essentials of Mental Health Research'** course that took place recently. Then circle below which category highlights the level of skill or experience you feel you have currently. This is to help us tailor the refresher course to the needs of participants.

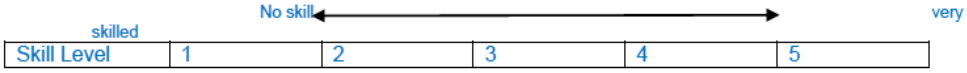
When scoring each area please use the following scale.

Current Skill or Experience Level:
1-no skill or experience **2**-some skill or experience **3**-reasonable skill or experience **4**-quite skilled or experienced **5**-very skilled or experienced



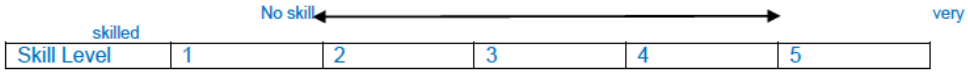
1. **What is research?**

Current Skill or Experience Level:
1-no skill or experience **2**-some skill or experience **3**-reasonable skill or experience **4**-quite skilled or experienced **5**-very skilled or experienced



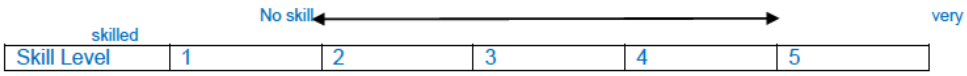
2. **Research theories and methods**

Current Skill or Experience Level:
1-no skill or experience **2**-some skill or experience **3**-reasonable skill or experience **4**-quite skilled or experienced **5**-very skilled or experienced



3. **Background to service user research**

Current Skill or Experience Level:
1-no skill or experience **2**-some skill or experience **3**-reasonable skill or experience **4**-quite skilled or experienced **5**-very skilled or experienced



4. How to find information

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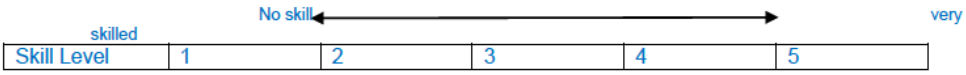

5. Completing a literature review

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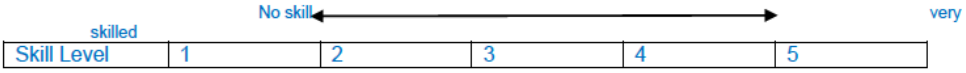

6. How to create a research question?

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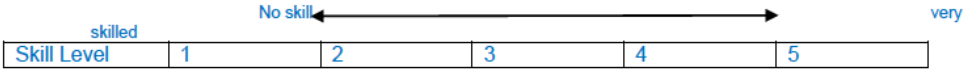

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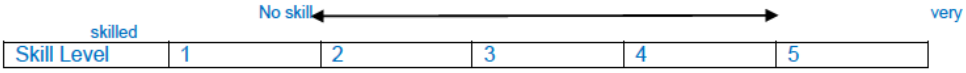

8. Skills of a researcher- interviewing, focus groups and data collection

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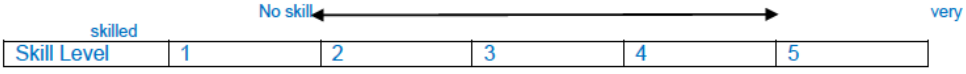

9. Being an unbiased researcher

Current Skill or Experience Level:
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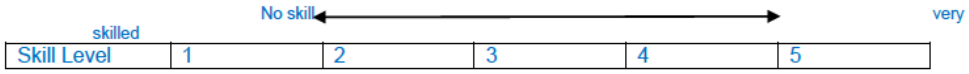

10. Responsible, legal and ethical issues in research

Current Skill or Experience Level:
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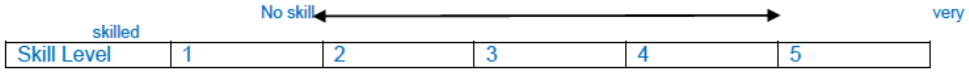

11. Completing large scale research – why is this important?

Current Skill or Experience Level:
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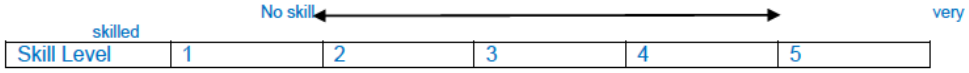

12. Pharma industry trials, what the industry wants from MHRN

Current Skill or Experience Level:
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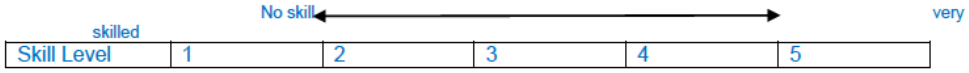

13. Gaining ethical approval – the role of ethics committees

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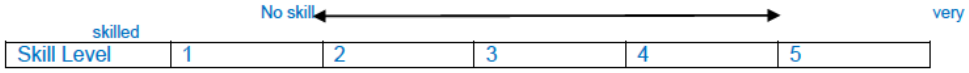

14. User involvement in large scale research

Current Skill or Experience Level:
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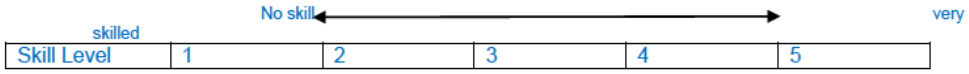

15. What is data analysis

Current Skill or Experience Level:
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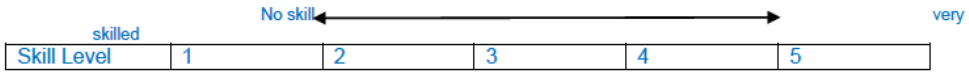

16. Interpreting data

Current Skill or Experience Level:
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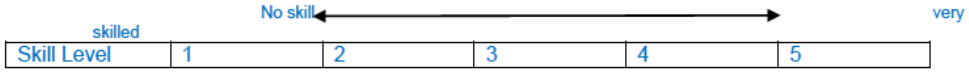

17. Report writing – writing up your research findings

Current Skill or Experience Level:
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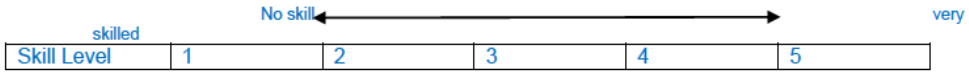


Is there anything in the above areas you would like to see covered in a refresher course?

About you

I am a user or former user of mental health services

I am a Carer, Friend/Relative of someone with a mental health problem

Please return the completed form by Friday 20th January 2012, to HeartofEnglandHub@bsmhft.nhs.uk or post it to Sonia Minteh, MHRN, HoE Hub, Radclyffe House, 66-68 Hagley Rd, B16 8PF.

If you have any further queries regarding the course you can contact me on 01216784314. If I am unavailable please contact Team Administrator Kim Fitzgibbons on 01216784326.

Thank you

Appendix 4 - Post-Course Questionnaire

Training Needs Assessment

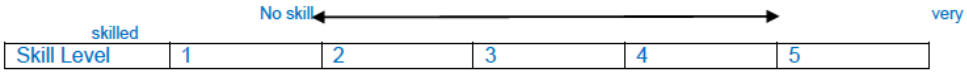
Developing Service User and Carer Research Skills

February 2011

Please read the synopsis of the **'Refreshing your Research Knowledge'** course that you recently completed. Then circle below which category highlights the level of skill or experience you feel you have currently. This is to help us evaluate the impact attending the training has had on meeting your learning needs.

When scoring each area please use the following scale.

Current Skill or Experience Level:
1-no skill or experience **2**-some skill or experience **3**-reasonable skill or experience **4**-quite skilled or experienced **5**-very skilled or experienced



1. What is research?

Current Skill or Experience Level:
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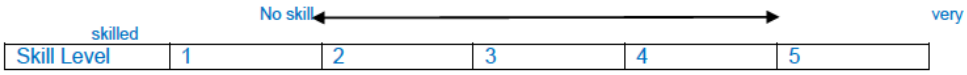

2. Research theories and methods

Current Skill or Experience Level:
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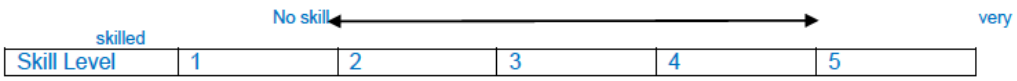

3. Background to service user research

Current Skill or Experience Level:
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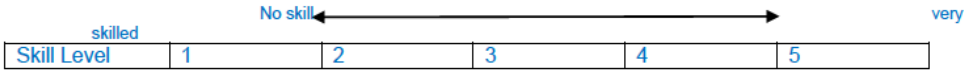

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Current Skill or Experience Level:
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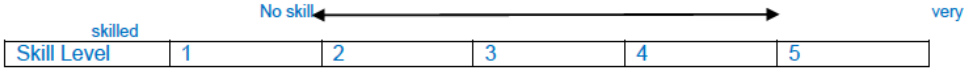

5. Completing a literature review

Current Skill or Experience Level:
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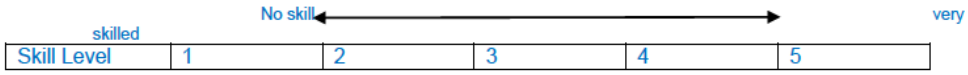

6. How to create a research question?

Current Skill or Experience Level:
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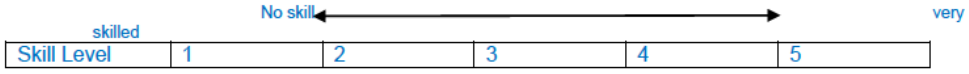

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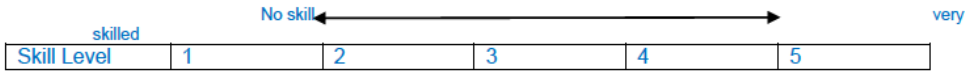

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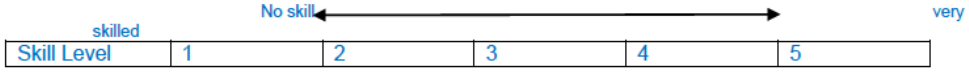

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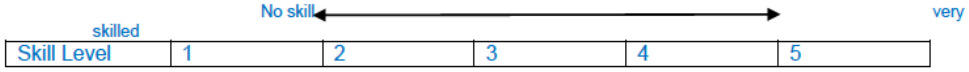

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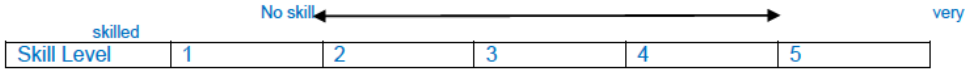

11. Completing large scale research – why is this important?

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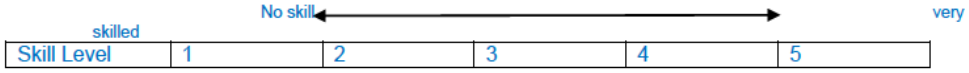

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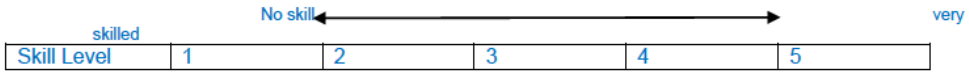

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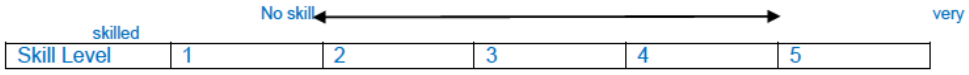

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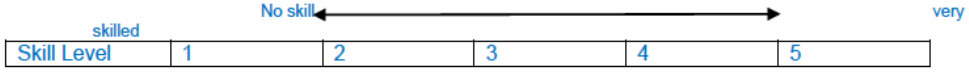

15. What is data analysis

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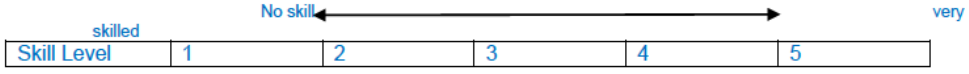

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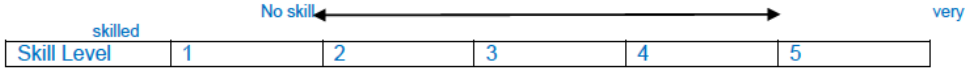

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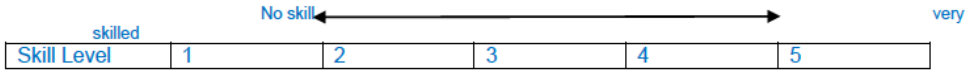


Were there any of the above areas you would have liked to have covered in more detail?

About you

I am a user or former user of mental health services

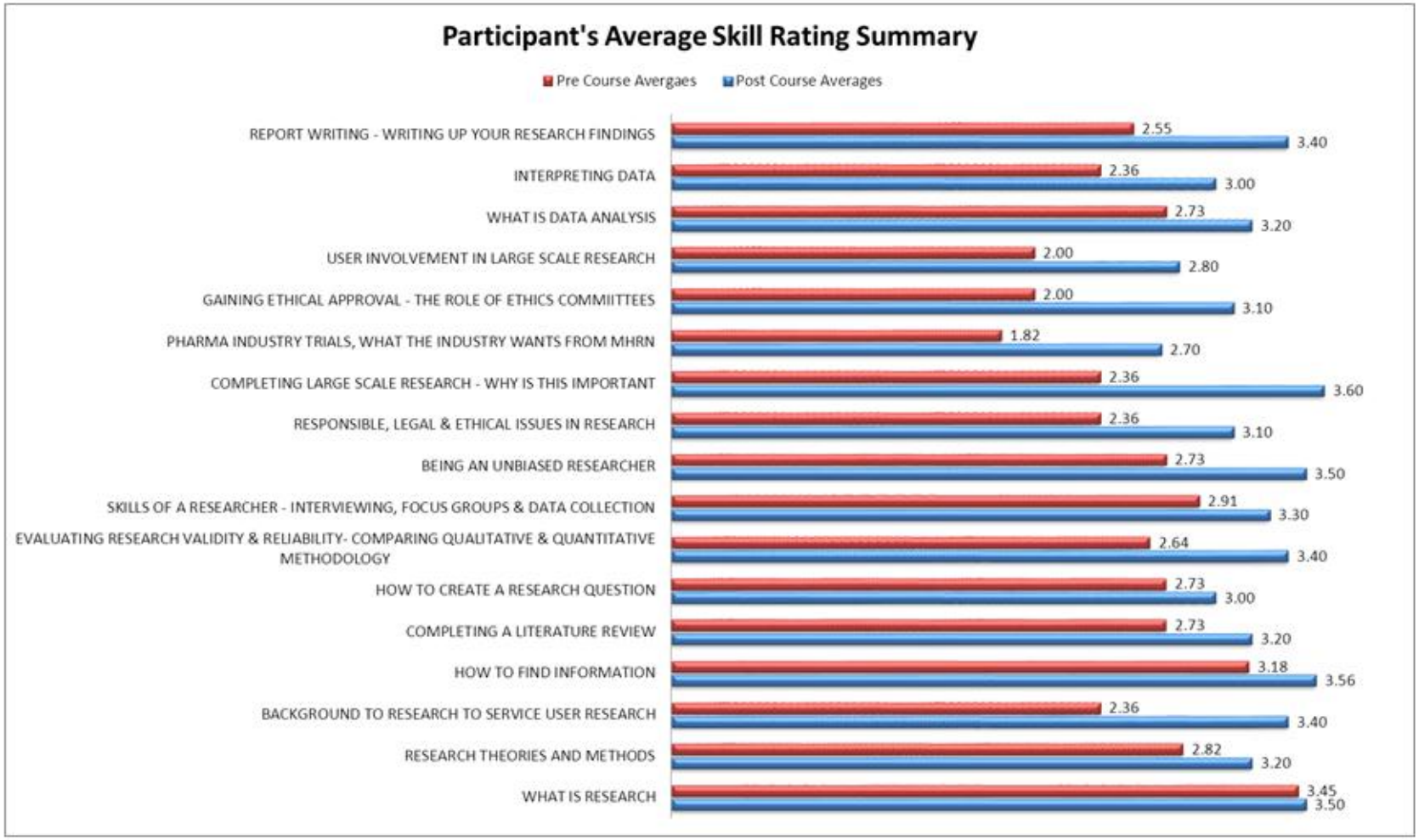
I am a Carer, Friend/Relative of someone with a mental health problem

Please return the completed form to Sonia Minteh, MHRN, HoE Hub, Radclyffe House, 66-68 Hagley Rd, B16 8PF.

If you have any further queries regarding the course you can contact me on 01213014314. If I am unavailable please contact Team Administrator Kim Fitzgibbons on 01213014326.

Thank you

Appendix Five – Refresher Course - Participants Pre and Post Skills Ratings



Appendix 6 – Refresher Course - Raw Data

1. **Please enter the number of sessions that you attended**

Attended all sessions – 10

2. **Did the training meet your expectations and objectives?**

Yes - 6
Yes on the whole - 1
Yes, more actually. Was very interesting with passionate people, I have learned a lot - 1
Yes (and more) - 1
In some ways it did as it refreshed my existing knowledge – 1

3. **If not please say why?**

Left blank – 8
I anticipated learning a bit more about quantitative - 1
In other ways it didn't because we did not have enough of an opportunity time to practice theoretical knowledge - 1

4. **What did you like about the training course?**

Reassured me that I did know things that I had not been pretending to know – 2
It was varied and covered a lot of research issues – 2
Freedom to ask for particular areas to be covered – 1
Interactive but quite coherent – 1
I enjoyed it being not too formal – 1
Shared experience and the diversity between course participants – 1
Clarity, breadth/scope, questioning approach, lots of useful information – 1
Enlightenment – 1
Meeting other people with mental health problems who are very interested in research -1

5. **What didn't you like about the training course?**

Left blank – 3
Nothing – 1
Too short – 1
A lot of information to take in – needs to be read again and again – 1
The speed of it – 1
At times I felt that things were a bit lacking in structure – 1
First wrote too many chairs, and then crossed it out. Then wrote nothing significant – 1
N/A – 1

6. **Are you interested in becoming involved in mental health research in the future?**

Yes – 5
Yes definitely – 1
Yes continue my involvement
Yes particularly perinatal MH research and also antenatal CBT and outcomes for perinatal MH onset. CBT & antenatal education - 1
Very much so – 1
I already am in a small way - 1

7. **If not why not?**

Left blank – 10

8. **Other comments**

Left blank – 6
4th floor room cramped, door sticking, food was nice, paper bags were a nice idea, would have liked more salad options – 1
I want to do the advanced course – 1
I think it would have been more useful to have this course as a e-learning package – 1
Very good, many thanks – 1

Service user / Carer

Service user – 7
Carer – 2
Left blank – 1
Circled carer and wrote plus person with lived experience (former service user)

Appendix 7 – Hand out Given to Course Participants regarding the Honorary Agreement

NHS Declaration Form

Before you can be considered for appointment in a position of trust with Birmingham & Solihull Mental Health NHS Foundation Trust we need to be satisfied about your character and suitability.

Prior to making a final decision concerning your application, we shall discuss with you any information declared by you that we believe has a bearing on your suitability for the position. If we do not raise this information with you, this is because we do not believe that it should be taken into account.

The information that you provide in this Declaration Form will be processed in accordance with the Data Protection Act 1998. It will be used for determining your application for this position. It will also be used for purposes of enquiries in relation to the prevention and detection of fraud. Once a decision has been made concerning your appointment, we will not retain this Declaration Form longer than is necessary.

The Data Protection Act 1998 requires us to provide you with certain information and to obtain your consent before processing sensitive data about you. Processing includes: obtaining, recording, holding, disclosing destruction and retaining information. Sensitive personal data includes any of the following information: criminal offences, criminal convictions, criminal proceedings, disposal or sentence.

Criminal Records Bureau Clearance

If you are applying to work with children or vulnerable adults, you may be asked to apply for a criminal record check. You will need to prove your identity as part of your application and a list of relevant documentation is provided with this hand out. All CRB checks within the NHS are completed online by the applicant who must also

provide original copies of relevant documentation to a named individual within the MHRN. This will be confirmed in due course.

The CRB check searches your details against criminal records and other sources, including the Police National Computer. The check may reveal convictions, cautions, reprimands and warnings. You, and your employer, will see the results of your search and from this the employer will decide whether they can still employ you.

Occupational Health

The protocol regarding occupational health checks is as follows:
All NHS staff must have a pre-appointment health check, which adheres to equal opportunities legislation and good occupational health practice.

Pre-appointment health checks are carried out to:

- Ensure that prospective staffs are physically and psychologically capable of doing the work proposed, taking into account any current or previous illness.

- identify anyone likely to be at excess risk of developing work-related diseases from
- hazardous agents present in the workplace.

- Ensure, as far as possible, that the prospective employee does not represent a risk to patients and that they will be doing work that is suitable and safe for them.

All checks must take into account the requirements of the Disability Discrimination Act 1995 (DDA) and reasonable adjustments must be made to ensure that people can work in the NHS regardless of physical impairment or learning disabilities.

Occupational health checks should be made once a job offer has been made. Employers must make it clear to prospective employees that any offer of appointment is conditional pending the successful completion of pre-employment checks, including an occupational health check.

Occupational health checks are the final pre-employment checks employers must do as part of the *NHS Employment Check Standards*.

Eligibility to Work

In accordance with the Asylum & Immigration Act 1996, the Trust must verify that new recruits have the right to work in the United Kingdom. I must ask, therefore, for you to bring along with you prior to your commencement of employment and before attendance at the Occupational Health Department one of the following original documents:

- A document stating your national insurance number (e.g. P45, P60, NI or payslip) **or**;
- A passport certifying the holder to have the right of abode in the United Kingdom **or**;
- A document issued by a previous employer or relevant government agency, a certificate of registration or naturalisation as a British Citizen, **or**;
- A birth certificate, **or**;
- A United Kingdom residence permit, **or**;
- A work permit, or equivalent letter from the Home Office indicating permission to take up employment, **or**;
- Any other documentation not listed above which the prospective employee believes provides a right to work in the United Kingdom.

All new employees are required to provide the necessary documentation outlined in the Asylum and Immigration Act irrespective of race or nationality.
Should you require a work permit, this department on your behalf, will make an application. Until the Home Office has granted this clearance, you will not be allowed to commence duties within Birmingham & Solihull Mental Health NHS Foundation Trust.

Appendix 8 – Information Letter Given to Course Participants on the Advanced Course

24th May 2012

Involvement in Research Teams

As part of the programme, we hope to give the opportunity to become involved with local research teams. The basis of your involvement in the work of research team(s) will be due to your status as an 'expert by experience'. This refers to your experience of specific mental health condition(s) and/or more generally, your experiences of mental health services as a service user or carer of someone who has accessed these. Being involved in this way does not in any way imply you have capacity for work.

There are 2 ways in which you can become involved. One is on the basis of a 'Letter of Access' and the other is on the basis of an 'Honorary Agreement'. For both of these you will require CRB clearance.

It is for the individual to decide which option they choose to undertake.

Letter of Access

A 'Letter of Access' would allow you to be involved in some of the work of the research team, but would not allow you to go into clinical areas or have any contact with service users (e.g. observing interviews or discussing consent). In principle, a 'Letter of Access' should be

transferable to allow you to go into other NHS Trusts, but this cannot be guaranteed: each NHS trust has responsibility for deciding who it allows in.

Honorary Agreement

An ‘Honorary Agreement’ gives you full access as a ‘research fellow’ and would allow you to go into clinical areas or have any contact with service users as agreed with the research team. It should be transferable to allow you to be involved with other NHS Trusts.

However, to get this you have to get Occupational Health clearance. This is required due to the likelihood you will be visiting clinical areas or peoples’ homes, therefore a vaccination for Hepatitis B may be required. Unfortunately this form does not fit the purpose in which we want to use it but we have been assured by the Trust and Team Prevent (occupational health service providers) that this form is used for service user volunteers and does not imply that you are fit for work by the nature of you completing it and receiving occupational health clearance.

The Occupational Health form you complete is confidential to yourself and the Trust and cannot be released without your permission. However we acknowledge that it does contain wording that might be interpreted as evidence of being fit for work.

Payment and Expenses

Your involvement with research teams that we are currently organising to start in July is not paid.

In line with the Department of Health "Reward and Recognition: *The principles and practice of service user payment and reimbursement in health and social care. A guide for service providers, service users and carers*" document, reasonable travel expenses will be reimbursed to you on production of receipt(s). Refreshment and food costs (termed subsistence) will be reimbursed following the Birmingham and Solihull Mental Health NHS Foundation Trust policy.

This is detailed below:

- If involved in research work between 11am and 1pm then lunch can be claimed for up to the value of £5.
- Refreshments (tea, coffee, water etc) should be provided by the research team as part of their office environment. If these are not, then you will be reimbursed for reasonable refreshment costs.

These policies are put in to place to ensure that public money is spent appropriately and carefully.

We have provided a booklet that helps you find out more about how your benefits may be impacted upon if you choose to take payment for involvement in research in the future. We can also give you access to a specialised service provided by Milton Keynes Citizens Advice Bureau who can advise you in a confidential way as to what you can earn and what impact any earnings could have on the benefits you may receive.

If you require this service, please get in touch with Jacqueline Smart, our Service User Development Officer.

Please contact her on jaqueline.smart@bsmhft.nhs.uk or tel: 0121 301 4341. Jackie works part-time so please be mindful of this when trying to contact her. We hope you enjoy this experience and being involved in research. Best wishes from the Suresearch and Mental Health Research Network team.

Appendix 9 – Evaluation Form

Advanced Course in Research Methods

Evaluation Form

Please circle the rating that closely matches your assessment of today's lecture

1. How would you rate the speaker/s?

Very Poor Poor Satisfactory Good Excellent

Further comments

……

……

……

2. Was the session presented in a way that was clearly understandable to you?

Very Poor Poor Satisfactory Good Excellent

Further comments

……

……

……

3. How would you rate the content of the presentations in terms of improving your research knowledge?

Very Poor Poor Satisfactory Good Excellent

Further comments

……..

……

……

4. Do you feel the hand outs were helpful and relevant to your learning?

Very Poor Poor Satisfactory Good Excellent

Further comments

……

……

……

5. Do you feel you had an opportunity to contribute your ideas to the session?

Yes No

Further comments

……..

……

……

6. Would you recommend the training to individuals with lived experience of mental health difficulties who have an interest in developing their research knowledge and skills?

Yes No

Further comments

……

……

……

7. We value your opinion and would be interested to hear how we could improve the training session. Please make any comments below.

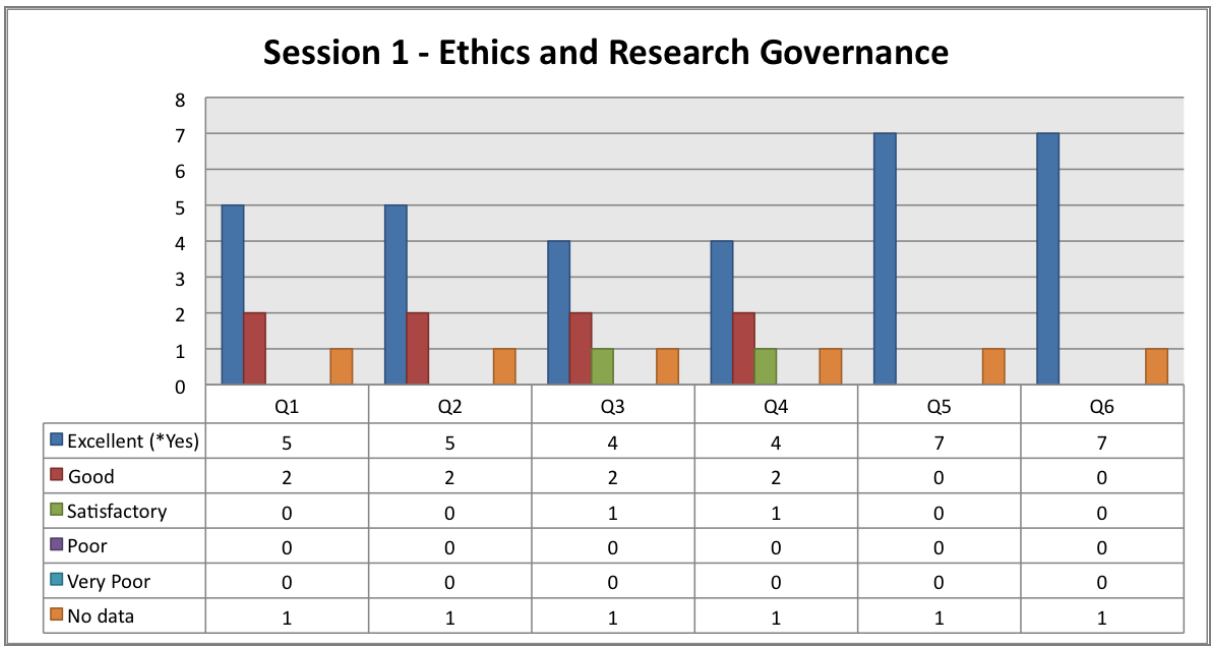
……..

……..

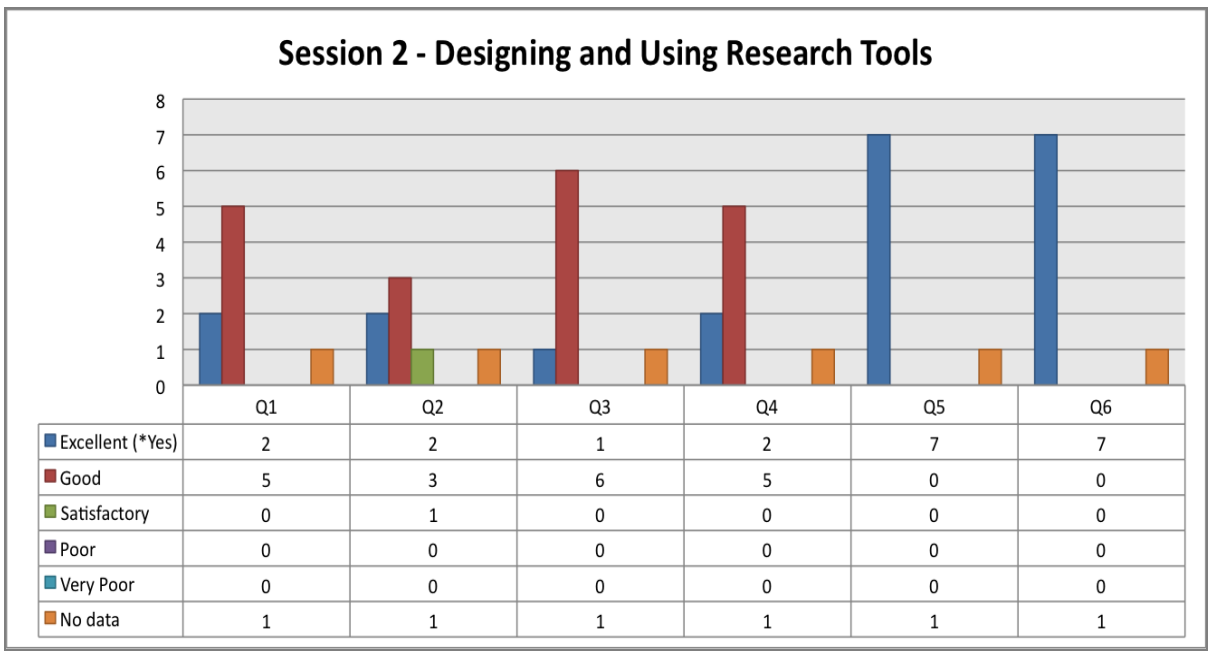
Please complete and return this form to Sonia Minteh at:
Mental Health Research Network
Radclyffe House
66-68 Hagley Road
Edgbaston
Birmingham
B16 8PF

Appendix 10 – Course Participant Feedback on Classroom Sessions

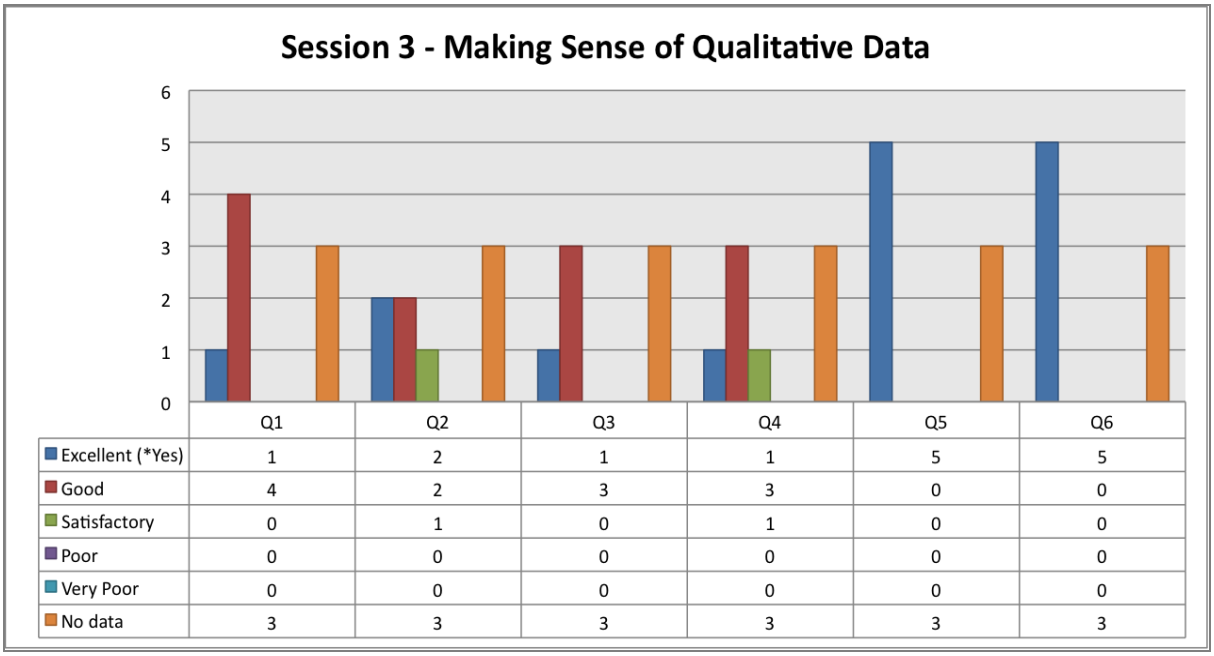
(* For questions 5 and 6 in each session, which required a 'yes' or 'no' answer, 'excellent' represents a 'yes' answer.)



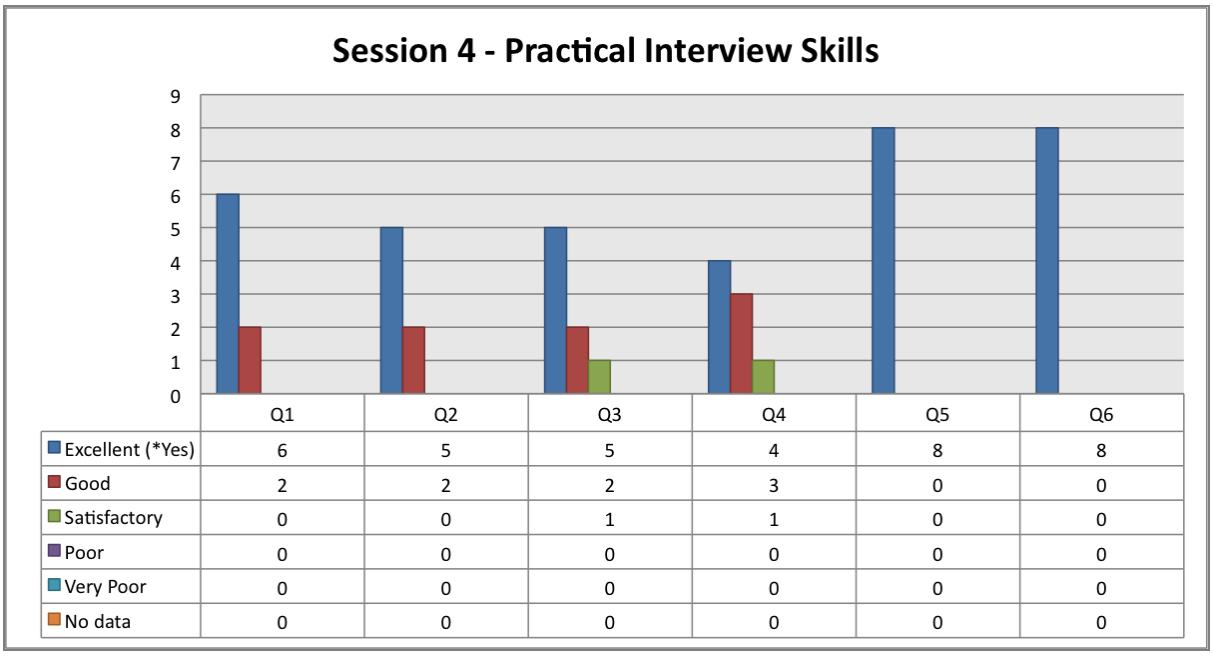
	Q1	Q2	Q3	Q4	Q5	Q6
Excellent (*Yes)	5	5	4	4	7	7
Good	2	2	2	2	0	0
Satisfactory	0	0	1	1	0	0
Poor	0	0	0	0	0	0
Very Poor	0	0	0	0	0	0
No data	1	1	1	1	1	1



	Q1	Q2	Q3	Q4	Q5	Q6
Excellent (*Yes)	2	2	1	2	7	7
Good	5	3	6	5	0	0
Satisfactory	0	1	0	0	0	0
Poor	0	0	0	0	0	0
Very Poor	0	0	0	0	0	0
No data	1	1	1	1	1	1

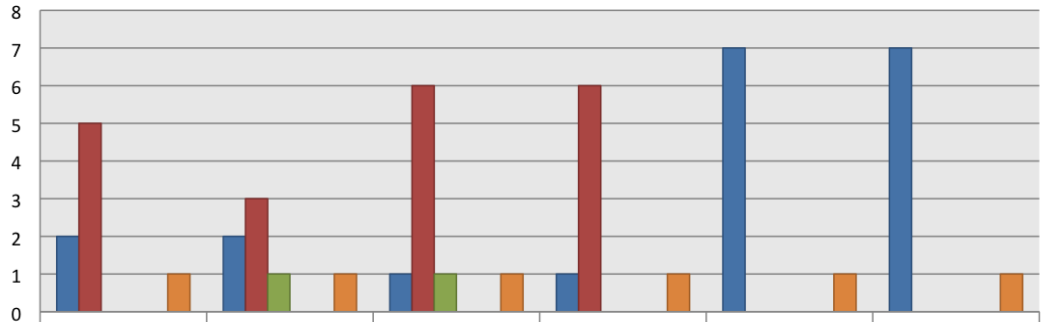


	Q1	Q2	Q3	Q4	Q5	Q6
Excellent (*Yes)	1	2	1	1	5	5
Good	4	2	3	3	0	0
Satisfactory	0	1	0	1	0	0
Poor	0	0	0	0	0	0
Very Poor	0	0	0	0	0	0
No data	3	3	3	3	3	3



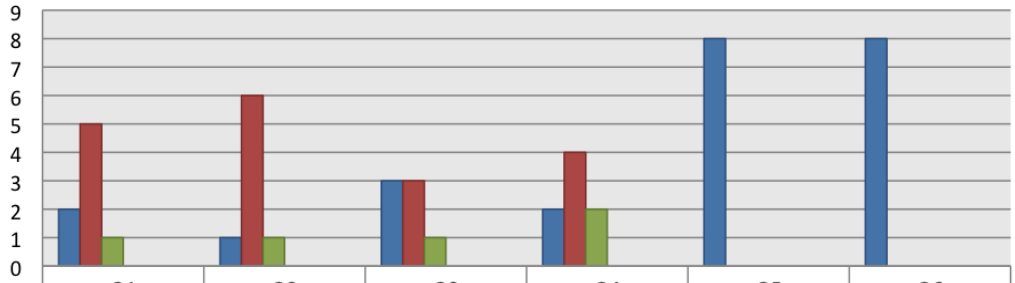
	Q1	Q2	Q3	Q4	Q5	Q6
Excellent (*Yes)	6	5	5	4	8	8
Good	2	2	2	3	0	0
Satisfactory	0	0	1	1	0	0
Poor	0	0	0	0	0	0
Very Poor	0	0	0	0	0	0
No data	0	0	0	0	0	0

Session 5 - Making Sense of Quantitative Data



	Q1	Q2	Q3	Q4	Q5	Q6
Excellent *Yes)	2	2	1	1	7	7
Good	5	3	6	6	0	0
Satisfactory	0	1	1	0	0	0
Poor	0	0	0	0	0	0
Very Poor	0	0	0	0	0	0
No data	1	1	1	1	1	1

Session 6 - Developing a Research Proposal



	Q1	Q2	Q3	Q4	Q5	Q6
Excellent (*Yes)	2	1	3	2	8	8
Good	5	6	3	4	0	0
Satisfactory	1	1	1	2	0	0
Poor	0	0	0	0	0	0
Very Poor	0	0	0	0	0	0
No data	0	0	0	0	0	0

National Institute for Health Research

Clinical Research Network
Mental health

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