



**National Institute for
Health Research**

Clinical Research Network
Mental health

Independent evaluation of the advanced training course for mental health service users and carers

Training course prepared and delivered by the Mental Health Research Network Heart of England Hub and Suresearch

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**Delivering research to make patients,
and the NHS, better**

Contents

| | |
|---------------------------------------|------------|
| Section 1: Summary | p4 |
| Section 2: Objectives | p6 |
| Section 3: Methods | p6 |
| Section 4: Feedback from interviews | p8 |
| 4.1 Course Participants | p8 |
| 4.2 Placement Providers | p15 |
| 4.3 Course Trainer | p25 |
| 4.4 Project Coordinator | p28 |
| Section 5: Discussion and conclusions | p34 |
| Section 6: References | p37 |
| Section 7: Appendices | p38 |
| Appendix 1 Questionnaires | p38 |
| Appendix 2 Consent Form | p50 |

Section 1: Summary

The Mental Health Research Network, Heart of England Hub-Suresearch Advanced Course for Mental Health Service Users and Carers has the objectives of providing the knowledge, skills and experience for effective participation by Mental Health Service Users in Mental Health research. The course was designed in partnership between Suresearch and the Mental Health Research Network, Heart of England Hub. This Report was commissioned in order to obtain independent feedback from participants and as discussed between Carly Cooper, Jacqueline Smart and Sonia Minteh. This report complements the Report prepared by the Project Coordinator, Sonia Minteh. The Report evaluates the Advanced Course with detailed references to Course Participant feedback, and also includes information about the Training Pilot.

The Advanced Course followed a 2-day Recall (syn. Refresher) preparatory session to bring Advanced Course applicants, some of whom had previously completed a Beginner Course, to the same level of understanding. The Advanced Course comprised Class (taught and interactive group work) and Placement ('hands on' research experience) components. Acceptance to the Advanced Course was in part based on an outline Research Proposal prepared by the course applicant; after completion of the Taught and Placement components of the Advanced Course. Participants gave presentations on their research proposal which was then critiqued in a group setting. Some course participants enrolled on the Advanced Course without attending the Recall session.

To determine whether or not the Advanced Course had fulfilled the objectives of preparing Mental Health Service Users for effective participation in research, and to evaluate the response to the Advanced Course of all those involved – Course Participants, Placement providers, Course Trainer and Project Co-ordinator, the Mental Health Research Network, Heart of England Hub and Suresearch commissioned an independent external evaluation of how well the Advanced Course had achieved the aims of preparing applicants for participation in Mental Health Research projects.

Evaluations took the form of semi-structured interview as follows:

- a) The interviewer prepared questionnaires to follow various themes (see Appendix 2) in such a way that the questions were a starting point to encourage interviewees to discuss matters that they thought were pertinent to their experience in relation to the Advanced Course.
- b) Interviews took place from January to mid-March 2013.
- c) Interviews were conducted at the Mental Health Research Network headquarters (Radclyffe House), in person or by telephone.

Course participants all thought that the course content was appropriate, that those involved in teaching and management i.e. Course Trainer, Course Facilitators, Placement Providers and Project Co-ordinator, communicated well and were welcoming and supportive. All course participants enjoyed the 2-day Refresher course prior to acceptance to the Advanced Course. Course participants particularly liked the interactive group nature of taught course material which helped them gain confidence and enhanced their learning experience in a group setting. Course participants were unanimous in the value of the Placements which provided 'hands on' experience not available otherwise. Placement topics varied according to what was available and feasible at the time and comprised joining a research team with a current research project or gaining experience in a NHS research environment with opportunities to experience a range of research and administrative- related activities. There were some difficulties of timetabling the Placements due in part to the time needed to obtain CRB clearance and the need to comply with Occupational Health requirements for Honorary Contracts.

Placement Providers were unanimous in their praise for the learnt skills and effective participation of course participants in research settings. The end-of-course presentations, a test of the knowledge and skills learnt during the Advanced Course, and of the effectiveness of teaching, exceeded the expectations of Course participants and Placement Providers – one course participant said she was '*euphoric*' that she had succeeded in making her

presentation; a Placement Provider said the presentations turned out to be ‘a *celebration of course participant achievements*’; the Course Trainer described as ‘*heart-warming, the knowledge and skills learnt by course participants and also how course participants had developed in a personal sense*’. Placements took place at the end of the taught part of the Advanced Course. Short consolidation sessions directly after specific modules such as Ethics and Governance, were suggested as an alternative or addition to future courses-

Course participants and Teaching staff described the therapeutic effects of the Advanced Course as measured by increased self-confidence in group settings, during the Placements and in the end-of-course presentations.

Section 2: Objectives of the Independent Evaluation of the Advanced Training Course

The interviews were commissioned to obtain an external i.e. independent evaluation of a) what course participants felt about the Advanced Course – Taught and Placement components and b) the learning outcomes of the taught and placement components of the Advanced Course hence the extent that the Advanced Course met the key objectives of enhancing the knowledge, understanding, skills and experience of Mental Health Service Users in order that they may participate effectively in Mental Health research projects. By ‘effective’ I mean being able to participate in a research setting, to provide ideas, questions and analysis from a perspective of a Mental Health Service User or Carer hence to complement the contributions of health care professionals.

Originally, only course participants were to be interviewed. Following discussions with the Mental Health Research Network, Heart of England Hub, interviews were extended to include Course Trainer, Facilitators, Placement Providers and Project Co-ordinator and hence to provide a holistic evaluation of the Advanced Course.

Section 3: Methods

Interview questionnaires were prepared by the Author and revised in consultation with the Mental Health Research Network team and the Advanced Course

Steering Group (Appendix 1). Questionnaires were provided to interviewees before the interview to provide time for reflection. The Questionnaires followed a semi-structured format and were intended as guidelines for interviewees to tell their story in their own words. Interviews were face-to-face or by telephone and took place at Radclyffe House, an environment that was familiar to interviewees and which ensured privacy. Interview Consent forms were signed by interviewees before the interview (Appendix 2).

Face-to-face and telephone interviews were recorded on a password protected Dictaphone provided by the Mental Health Research Network, Heart of England Hub. The author made handwritten notes in a notebook dedicated solely to the Independent Evaluation interviews

Dictaphone files were downloaded to the Mental Health Research Network IT system, and transferred to a Trust laptop. All IT equipment was password protected and encrypted according to the Birmingham and Solihull Mental Health Trust standard procedures.

Interviews were originally planned to last about 40 minutes. In practice, interviews took longer due to the enthusiasm of interviewees to tell their story, with some interviews lasting up to an hour. This provided support for the decision to use of semi-structured interviews.

Interviews were written up at the Author's home on a personal laptop (up to date Norton virus checker). Dictaphone recorded interview files were archived at the Mental Health Research Network, Heart of England Hub for future reference; files were not transcribed due to time constraints. For clarity, interview feedback was reported here using the original questionnaire headings. A maximum of three *verbatim* quotes were selected out of the many, for inclusion in the feedback. Other relevant quotes are available if required.

At the end of the project, all notes, together with relevant files on the interviewer personal laptop were transferred to Mental Health Research Network, Heart of England Hub for archiving and the information remains their property. All files related to the Independent Evaluation on the Interviewer personal laptop (with the exception of the project diary) were shredded. No records (excepting the project

diary) and no personal information about course participants have been retained by the Author.

Section 4: Evaluation of Advanced Training Course

4.1. Interviews with Course Participants

Part 1. The Advanced Training Course - the preceding Recall Course

Course Participants mentioned the considerable value of the Recall Course as preparation for the Advanced Course. The Recall Course was a valuable aid to help applicants confirm whether or not to continue to the Advanced Course, to help revision, therefore to bring applicants to a similar level of knowledge, skills and understanding:

“The Recall Course confirmed my decision to take part in the Advanced Course”.

“The Recall Course was very useful and gave me confidence to learn about the Advanced Course - it was ‘ramp leading up to the Advanced Course’”.

NB: Not all Course Participants attended the Recall Course.

Part 1. The Advanced Training Course – taught modules

It quickly became apparent that course participants had gained a comprehensive understanding of what is meant by research and the role and value of Patient Public and Carer Involvement (PPI: here Mental Health Service Users and Carers) experience in complementing the knowledge and experience of professional Mental Health researchers. Course participants commented that the Advanced Course content was relevant and appropriate and they particularly valued the interactive practical sessions during the taught component of the Advanced Course. Course participants complimented the Facilitators and

Placement Providers for their support, sensitive interactions with participants, and their communication skills:

“Teachers were supportive, smiled a lot and this helped my confidence for taking part in the Placement”.

Q1. What do you understand by the term ‘research’?

Course participants had a sound understanding of what, why and how research is done including the need and value for questions especially those that are unconventional and challenge accepted thinking. Representative answers were:

“Trying to find answers to questions and to consider new questions”.

“Formulating questions, gathering data, analysing data to provide answers; (supplementary Q by interviewer: ‘What if answers are not as expected?’ A: “well, that is part of research”).

“A systematic enquiry about anything; a hypothesis to prove; or just an area of study”.

Q2. Why do you think research is important in health research?

Course participants had a comprehensive understanding of the role of research in Health and Mental Health studies, including the need to obtain data to answer research questions and to validate or otherwise established treatments and interventions, the latter of particular importance for Mental Health Service Users. Representative answers were:

“Health care is based on the scientific model therefore research is needed to obtain data and validate ideas and interventions”.

“Obtaining data on how different people feel – including attitudes to Spirituality; self-perception of symptoms; being loved; purpose in life”.

“There are moral reasons for providing opportunities for public, patients and carers to be involved in research”.

In order to provide answers, research methodology may need to be revised during a project. For example, one course participant described a vaccination programme in the ‘Third World’, first using old-type analogue maps to locate target populations but which achieved <50% participation of target; the methods were then changed to modern digital maps to improve location of populations in remote areas; participation increased considerably, hence the revised methodology helped the research achieve targets and increased translation into health practice.

A second course participant described how even ‘identical’ twins may vary in their health characteristics for reasons that are not fully understood, thus demonstrating an understanding by the course participant of the need for further research to evolve our understanding of why and how the outcomes of interventions vary between people.

A third course participant commented that ‘negative’ results might not be reported:

“If the results on the effects of Cognitive Behavioural Therapy (CBT) on post-traumatic stress proved negative then there is the possibility that data would not be reported”.

This comment demonstrated that the course participant understood a potential weakness in the completeness of reported of research data.

Q3. How can service users and carers help to design research project?

Course participants described carefully thought-out and logical views on the essential role of Service Users in health research:

“Service users are experts by experience and have a treasure chest of experiences; each person is different with different experiences”.

“Service Users help with the choice of research topic; it is doubtful if a health care professional can actually experience a Mental Health Service User role”.

“Research is done with our money and we (Service Users) have a stake in health research”.

One course participant commented: *“Not all researchers are convinced about the need to include Service Users in research”*, thus recognising the continuing need to convince health care researchers of the value of the lived experience of Service Users in health research, something that is not limited just to Mental Health research.

Part 2. The Course Placement

Course participants commented that the Placement component was an essential part of the Advanced Course, and that the taught part of the Advanced Course provided an essential preparation for the Placement.

Q 1 a. Tell us how the Training Course helped you to contribute to the research project.

“The Placement was hugely helpful; I learnt by doing and practising what I had learnt in the Advanced Course”.

“The Placement was brilliant – the (taught component of the) Advanced Course meant that I felt I had something to offer the Placement”.

“(The Placement) gave me more idea of what is actually involved in research. In my case ‘it has helped filled the gaps in my knowledge of what research is actually about’”.

Q1 b. Tell us how the Placement helped you gain confidence.

Course participants firmly believed that their experience of the Advanced Course, including the Placement, contributed greatly to their self-confidence:

“Facilitators were very respectful and ‘actively listened’”.

*“The Advanced Course increased my knowledge of Self and where I wanted to get to; it increased my confidence when I realised that ‘I **can** do’”.*

“The atmosphere in the research team was inclusive, OK to ask questions, which were valued by others (in the research team)”.

Q1 c. How did you find others in the Research team respond to your questions and participation?

Course participants consistently commented favourably on the inclusive and welcoming response of Placement staff and research teams:

“The team was very supportive. I felt wanted and part of the team”.

“Others in the (research) team were supportive, non-judgmental, they listened actively, without personal intrusion; they made me feel I wanted to be there, that I was not a nuisance”.

“The Advanced Course has helped me reclaim my self-confidence for the Placement”.

Q1 d. Now that you have taken part in the Advanced Training Course and Placement, tell me about other research and/or business opportunities you have been involved in OR how the Training Course has helped you look for new research and/or business opportunities.

Course participants all thought that completing the Advanced Course had given them the skills and experience to take part in Mental Health research, and some course participants are already doing so:

“As a result of the Advanced Course, I have helped prepare a leaflet on partnerships (between MH Service Users and health care professionals) to encourage research”.

“As a result of the Advanced Course I now take part in Steering Groups and am involved in a research project on drugs; I interview friends and family as part of a support network”.

“I have reviewed three research papers on autism”.

Q1 e. Tell us what worked well for you in the Advanced Training Course and Placement.

The consistent response of course participants was that most aspects worked well not just in terms of the course content but also the supportive and sensitive manner of presenting taught material, the Placement and the administrative arrangements:

“The active listening and being part of something bigger than Self; other researchers believing in me”.

“...being together in a group and sharing different experiences and skills”.

“Giving a presentation at the course end: I felt nervous to start with but elated when I had finished!”

And an administrative matter: *“Being reimbursed (travel expenses) on the same day”.*

Q1 f. Tell us about what didn't work so well and what changes you would like to see in future courses.

Course participants discussed three administrative aspects: 1) the position of the Placement in the Advanced Course; 2) the time for CRB checks and 3) Occupational Health issues with Honorary Contracts:

“I would have preferred if the Placement had started half way through the Advanced Course, otherwise it is difficult to fit in with my job”.

“Perhaps the space between taught and placement components could be shorter”.

“I didn’t manage a full Placement because of requirement for vaccination (Occupational Health requirement for Honorary Contracts)”.

“CRB clearance was slow: I applied in April but approval not received until October when the course had finished”.

One course participant thought that one seminar session should be revised:

“In one seminar there were three talks about similar subjects – could have been more varied and shorter”.

[Author: this was the only criticism of course content in all the interviews.]

Part 3. Summary

Q1. To round off would you like to recommend the Advanced Course to others and if so the particular aspects that you liked, and who else do you think would benefit from the Course?

All Course Participants strongly recommended the Advanced Course:

“Definitely; the key was having Facilitators who were expert in Mental Health and qualitative research”.

“Absolutely recommend to anyone involved in a Research project”.

“Advanced Course has really made a (positive) difference to my life”.

“I particularly recommend the Placement because (you) can’t get the actual experience any other way”.

[Author: the question on what aspects were liked is answered in Part 2 Q 1e]

Q 2. What other Training Courses have you attended or are planning to attend. And how do you think they compare with the Mental Health Research Network-Suresearch Advanced Training Course?

One course participant had taken a course on *“mental health awareness and training the trainer”*.

A second course participant: *“I took a) an Open University course on Mental Health (which was academic and had no practical component) and b) Mental Health first aid instruction aimed at informing the public how to respond when a MH person is distressed”*.

A third course participant: *“just the Mental Health Research Network Recall Course, apart from courses long ago”*.

A fourth course participant commented: *“I am involved in Suresearch”*.

The remaining course participants had not taken other courses.

4.2 Feedback from Placement Providers

Part 1. Your role of Placements in the Advanced Course

Q 1. What difficulties or restraints, if any, have you experienced in the past obtaining effective participation of Mental Health Service Users in Research?

Difficulties were few and centred on the availability of funds at the preparation phase of a Project, timetabling, and the time taken to obtain CRB and Occupational Health clearance. A Provider in one health Trust commented:

“A problem is that research projects have no funding until a proposal is accepted and this makes it difficult to ask Service Users to take part at the early design

stage. However the Research Design Service does now offer bursaries for Service Users to be involved at the consultation stage and this has helped”.

“Our increased experience of involving MH Service Users has led to the idea of involving Service Users at all stages of a proposal hence the idea was gelling that we would gain from the experience and ideas of Service Users, which is an example of ‘added value’.

“We realised that there were differences in perception when Service Users conducted interviews in comparison with academics doing the interviewing”.

Placement Providers thought that implementation of the Advanced Course was justified as a means to widen the availability of Mental Health Service Users with appropriate skills and experience in Mental Health research:

“Sometimes we find that it is the same people who become involved in research because of their experience and skills – some have an academic background - but we want to widen the range of Mental Health Service User experience”.

“Part of the idea was to look for more capacity for Service User participation in Mental Health research”.

A difficulty can be the time taken to obtain Approval and funding for a research proposal hence the process may seem disjointed to Service Users:

“It would be better to have a full time Service User Lead who can keep Service Users informed of progress of a research proposal”.

Q 2. What outcomes did you expect a Placement to provide?

Q 2a. Mental Health research in general

Providers had a clear understanding that the Placement was:

“To give course participants ‘hands on’ experience of research, to ‘demystify’ research; to realise that much of research is ‘ordinary’.”

One Provider, however, was less certain, explaining that more information was needed about the taught component of the Advanced Course.

Q 2b. Your Provider organisation

One provider commented that providing a Placement *“was more an act of good faith to train researchers who may be out of the Trust region – we organise Service User training anyway”*.

Otherwise it was the opportunity to increase the availability of Mental Health Service Users for research projects that was key.

Q 2c. Course Participants

All Providers agreed that the Placement was to give ‘hands on’ experience of research in an NHS setting:

“To provide hands on feel of research in the NHS, the difficulties, the processes of research governance”.

“To demonstrate that in the NHS it is the translation of research into real life that is key”.

“So that a course participant can realise that participation in research is all about making relationships and understanding the organisation”.

“Provide people with increased knowledge”.

One Provider commented: *“The Advanced Course is not so much about imparting knowledge but more about giving confidence in critical thinking and the confidence and skills for Service Users to ask awkward questions”*.

Q 3. Apart from the Placement did you make any contributions to the development and delivery of other parts of the Advanced Course?

In general Placement Providers were not involved in the development of the taught part of the Advanced Course. However, one Provider was a member of the Advanced Course Steering Group, hence helped develop the Advanced Course content and structure.

Part 2. Placement Delivery

Q1. When were you approached about offering a placement for the training course and how?

One Provider confirmed that the first contact was via a telecon from the Project Co-ordinator, then by the Provider organisation line manager, and was processed by Human Resources. By virtue of her staff position the Provider was able to fast track the administrative process. Other Providers confirmed that they were first approached by telcon by the Project Co-ordinator.

“By telcon from the Project Co-ordinator and quite late in the day”

Two Providers didn't remember exactly, but thought contact was via the Hub Manager and/or the Project Co-ordinator

Q 2. How many Placements were you able to offer?

Providers mostly offered a single Placement. One Provider provided a single Placement but could have offered up to three Placements but only if they had been at the same time.

A second Provider offered several Placements: *“(We offered) several including CLAHRC, Research Nurse on drugs; Dementia; Quantitative analysis”*.

Q 3. How did you decide what Placement topic to offer?

Choice of topic depended on the availability and feasibility at the time of the request e.g. where the Trust covered an extensive area as with the Coventry

Trust when the Placement comprised early intervention; seminars and some active research.

Three Placement Providers commented:

“...topic choice depended on what was available and realisable due to timetabling”.

“Depended on what was available”.

“We didn’t really need the 5 days in the one session as allocated. Research ebbs and flows therefore better to spread the Placement accordingly so that the course participants can be actively involved”.

Q 4. What steps did you take to prepare the research team for the Placement?

Preparation depended on the nature of the placement i.e. whether in a research group or a more widespread experience in an NHS research setting. A typical response was:

“Placements were first discussed with the research team and staff supporting the Placement; in the end we discussed Placements at weekly meetings”.

For some Placements, there did not appear to be a need for much prior discussion.

Q 5. What, if any, difficulties did course participants have attending all Placement Sessions?

The few difficulties commented on included timetabling and, in one Trust, the need for transport within a large area to the placement site when the placement was spread over a period of one month rather than a single 5-day block.

Three Placement Providers mentioned the time taken to obtain CRB checks and Occupational Health clearance, a pre-requisite for Honorary Contracts from the Hospital Trust. Typical responses were:

“It is essential that the CRB and Occupational Health processes are started at the onset of the course, if not before”.

“Difficulties are with timetabling. Taking part directly in research projects is difficult as there is a need for lots of Approvals. Would be best to involved with a live project and then to identify a time for the Placement even if for a short time. A Placement has to be worthwhile for the Trust”.

Q 6. What was your role in providing support for course participants in their Placement?

Course participants generally needed little support. Nevertheless opportunities for support were provided by an independent mentor or by the Placement Provider when support was *‘needs lead’*.

On the day of arrival, one Placement Provider met the course participant who was introduced to the staff to get a feel for the research. The plan was to meet the course participant again at end of Placement to review progress but the placement was not successfully completed.

Q 7. What, if any, problems or difficulties arose during the Placement and how did you resolve them?

The only problems mentioned centred on Human Resource bureaucracy (Occupational Health checks) and the time taken to obtain CRB clearance (two placement providers), timetabling and travel time when the Placement involved a range of health care professionals working in different places.

Providers thought it was essential to start the CRB and Occupational Health check processes as early as possible (see Placement Providers: Part 2 Q 5.)

Part 3. Outcomes of Placement

Q 1. How do you think the Placement prepared the course participant?

Placements provided course participants with the *'hands on'* experience of what research is like and hence what is required to make an effective contribution:

"Placements provided opportunities to discuss the processes of research, to learn about new ways of thinking and to ask and reply to questions".

"Placement provided opportunities to think how to challenge research e.g. research design; experience of collecting data in different settings such as in-patient and out-patient settings and clinics; and to experience different situations e.g. doctor and clinician, hands on experience of research in Mental Health populations".

Q 2. Describe the changes in course participant response during the Placement e.g. interactions with each other and with the research team, making suggestions and asking questions and evidence of learning.

Course participants soon gained the confidence and skills to interact positively in group settings, being respectful of the contributions of other course participants. Course participants were in fact very supportive of each other. In addition:

"Course participants were fired up and enthusiastic".

"Certainly, group interaction increased as course participants became aware of the realities of research"

Two course participants had already had previous experience of interactions with Mental Health Service Users and Health Care Professionals and their experience contributed to the group interactions in the Advanced Course when they continued to be enthusiastic.

Q 3. Describe how the research team responded to the Placement course participant.

Independently of whether the Placement was in a research team or was a more widely based experience in an NHS research setting, the response of providers to the Mental Health Service Users was positive:

“The team response was very positive. Team was impressed at the open-mindedness and presentational skills of the Service User”.

“Everyone in the organisation e.g. Trust Research Executives, seminar presenters and management responded positively to course participants”.

“One Service User (course participant) analysed interview data and I was very impressed at the open-mindedness of the Service User and at the standard of presentation of results”.

Q 4. Were there any additional skills that you would like to include in future Training courses?

None of the Placement Providers said that other skills were needed for the Advanced Course although one Placement Provider would have liked more information on the Advanced Course syllabus:

“No, feeling able to join in a Research Group, feeling confident that an Mental Health Service User is able to join in, and to use the experience of taught components, rather than as being an expert on a specific taught part, was the most important outcome of the Advanced Course. This is strength of the course as demonstrated in their end-of-course Presentations - using their different knowledge and experiences to prepare and give an impressive and convincing presentation. As a result the presentation was a celebration and reflection on course participant achievement”.

Q 5. In addition to a Placement can you suggest other ways of Training Course participants obtaining practical experience of Mental Health research?

Placement Providers were satisfied with the aims and achievements of Placements i.e. to provide practical hands on experience of Mental Health research in NHS settings:

*“I wouldn’t want to do things differently – it was the combination of shadowing, getting data, data analysis, team discussions and then the course participant realising for ‘himself’ that ‘he’ **can** do....”.*

“It would be nice if there were opportunities for course participants to do a small piece of research with NHS staff, where Approval for involvement is easier to obtain; and to join in when something is happening”.

A second Provider thought that experience could be gained in Health Care settings such as Ethics and proposals submitted to e.g. the NIHR Research for Patient Benefit programme.

Q 6. Placements were at end of the taught part of the Advanced Course. What do you think about including a Placement at other stages of the Training Course?

The general consensus was that Placements were most appropriate when they followed the taught part of the Advanced Course. However one Placement Provider suggested that, in addition to the Placement as timetabled:

“There could be additional opportunities during the taught part of the Advanced Course by alternating specific modules with short sessions of professional experience of the module topic hence to help to embed the course participant knowledge and understanding”.

A second Provider commented:

“I would prefer if Placements were in the form of discussions so gaining experience of specific aspects e.g. a day of discussions with a Research Governance Facilitator. Better for the Placement to be more directed and with several shorter individual placements”.

One Placement, which comprised general experience in research settings, could have been implemented at any stage in the taught part of the Advanced Course but the Provider emphasised:

“For experience in a research setting the Placement would have to be after the taught component of the Advanced Course”.

As described elsewhere in this report, a key factor for implementation of Placements was the time taken to obtain the CRB checks needed for Honorary Contracts.

Q 7. Have you offered placements to course participants on other courses for Mental Health Service Users? How did the skills and experience of Advance Course participants compare with course participants from other courses?

None of the Providers had offered Placements before nor knew of other courses that included a Placement. In other words the idea of a Placement as an integral part of the Advanced Course and its implementation was new for Mental Health Service Users:

“No other courses that include Placements have been offered thus the Mental Health Research Network-Suresearch Advanced Course is unique in this respect”.

Q 8. Finally, now that course participants have received training would you be willing to accept or recommend Mental Health Service Users for a research project?

All Placement Providers said that they would be confident and willing to accept and to recommend Mental Health Service Users who had completed the Advanced Course:

“Yes, and I would expect a high level of skills and that the course participants would be competent to take part in decision making, reviewing policy and governance”.

“Absolutely and already working with one Mental Health Service Users”.

4.3 Feedback from Course Trainer

Part 1. Objectives, preparation and delivery of Beginner and Refresher Courses.

Q 1. What were the key objectives of the Beginner and Refresher Training Courses?

“It is National policy to involve Mental Health Service Users (in health studies). Without training, Mental Health Service Users may not have the confidence to know how to develop (a proposal) for clinical trials. Therefore the Training Courses equip Service Users with the knowledge, skills and experience to be able to criticise research; to develop their own ideas and to discuss the research ideas of others”.

Q 2. What was your role in inviting Mental Health Service Users to take part in the training?

“My role (as Course Trainer) was to develop the initial training (Beginner course) and to prepare the Recall course prior to the Advanced Training Course, working with Facilitators and with Professor Ann Davies; and to help evaluate the end-of-course Presentation”.

Q 4. How did you manage differences in course participant knowledge and skills for the Recall Course?

The Course Trainer had had previous experience as a Mental Health Service User, after which she returned to education and hence is now a Role Model for other Mental Health Service Users:

“Much of Mental Health research is qualitative and this is easier to understand than some of the methodology in quantitative research”.

“The Recall Course brought course participants up to speed. I felt I might have lost the course participants at times as there was a lot of ‘telling them’ and, possibly not enough interaction. I also wondered if I might have overloaded them as I condensed the Beginner Course into two days”. [Author: None of the course participants mentioned this.]

Part 2. Delivery and outcomes of training in the Beginners and Recall Courses.

Q 1. How did you evaluate the development of course participant knowledge and skills in the Beginner course?

Refer Part 3 Q 5.

Q 2. What changes did you notice in the level of course participant’s research knowledge and skills?

Refer Part 3 Q 5.

Q 3. What changes did you notice in the confidence levels of course participants?

The Course Trainer commented on the way that course participants responded to each other in group settings:

“The course participants interacted pretty well and were supportive to each other within the group; all had plenty to say and were very enthusiastic”.

Refer also to Part 3 Q 5

Q 4. What differences do you think the Beginner and Refresher courses will have on course participant future contributions to research proposal?

The Course Trainer was confident that the Advanced Course had achieved the objective of providing course participants with the knowledge, skills and understanding for effective involvement in Mental Health research projects:

“By completing the Advanced Course, Mental Health Service Users will be able and confident to develop their own ideas and those of others, to have the skills to criticise research proposals; take an active part in research e.g. by interviewing and writing Plain English summaries”.

“The Advanced Course will increase the pool of Mental Health Service User survivors who have the skills for research. My only doubt is whether there are enough opportunities (due to restrictions of finance) commensurate with their skills”.

Q 5. When you facilitated the Presentations following the taught and Placement parts of the Advanced Training Course, what effects did you notice on course participant understanding of Research methods and in the potential for participation as a Service User representative?

The Course Trainer was delighted at the progress course participants had made by completing the Advanced Course:

“It was heart-warming to see how far Mental Health Service Users had come; not just in intellectual aspects of learning, but how they had developed as people”.

It was also obvious to the Author how much the Course Trainer had enjoyed her involvement in the Advanced Training Course and the positive effects that the Advanced Course had achieved on course participants' knowledge, skills and understanding:

“I have enjoyed input all the time, I looked forward to the teaching and it was rewarding to see that the course participants were so enthusiastic”.

Q 6. Finally, what other thoughts have you on future courses to train mental health service users to participate in mental health research?

The needs and content of future courses will become evident as those who have completed the Advanced Course gain experience by involvement in research projects.

4.4 Feedback from Project Coordinator

Part 1. Objectives and preparation of the Advanced Training Course Advanced Course

Q 1. How did the idea arise for preparing an Advanced Training course for Mental Health Service Users?

The decision to offer an Advanced Course arose from the need to develop a previous Mental Health Research Network, Heart of England Hub-Suresearch Beginner course in order to train Mental Health Service Users at different levels of knowledge for participation in research projects:

“The idea of the Advanced Training Course arose from a previous Beginner course run by Suresearch. One conclusion was that there was a need for more courses at different levels of knowledge”.

Q 2. Describe what you wanted the Advanced Training Course to achieve.

The Project Co-ordinator had a similar understanding as described in the interviews with course participants and Placement Providers viz. to improve research knowledge and skills, implicit in which was the expectation of improving course participant Self Confidence:

“The Steering Group supported the idea that course participants would improve their research skills and also gain Self Confidence during the Advanced Course”.

Q 3. What was your role as Project Co-ordinator on the Advanced Training Course?

The role (Job Description) of the Project Co-ordinator was to implement the Advanced Course including the design of an Advanced Course information pack to promote the Advanced Course, identifying a course venue (University of Birmingham), and administrative matters such as arranging payment of travel expenses.

Before appointment of the Project Coordinator, a Steering Group had previously prepared a strategy for three Training Courses comprising Beginner, Recall and Advanced Courses. Following her appointment, the Project Co-ordinator joined the Steering Group to further develop the Advanced Course:

“Before my appointment a Steering Group had already made lots of decisions about course strategy e.g. Beginner; Recall; Advanced

“I joined the Steering Group for the Advanced Course and was involved in the subject content”.

“My role was to prepare advertising information, to publish the course; to identify venue (University of Birmingham), and act as the king pin (i.e. link) between course participants and course providers. The Steering Group also left me to advertise and organise the placement schedule”.

“I organised the Honorary Contracts for the Placement, something that took three months”.

4. Steering Group

a. What did you understand was the role of the Steering Group and what was your relationship to it?

“My role on the Steering Group was take part in monthly meetings from September 2011-April 2012”.

“We discussed progress and anecdotal feedback from the Recall and Advanced courses”.

b. What, if anything, would you change next time about your relationship with the Steering Group?

Following the appointment of Project Co-ordinator, there was an immediate involvement with organising and implementation of the Advanced Course. This left little time to be fully conversant with the Course details:

“I would have found it useful at the start to spend more time with the Steering Group discussing the Course including the course participant evaluation forms”.

5. How was the decision reached to offer the three levels (Beginner; Recall; Advanced) of training course?

The Mental Health Research Network, Heart of England Hub wanted to populate a database of Mental Health Service Users with different knowledge, skills and experience. The database would identify potential participants for Mental Health Research Projects:

“Right from the start there was recognition of the need for a range of different levels of involvement for Mental Health Service Users, hence for different levels of knowledge, skills and experience”.

Part 2. Delivery of Courses

Q 1. How were participants selected for the Advanced Training Course and what was your role in the selection process?

“Applicants to the Advanced Course provided information on their research experience to date, their availability and commitment to an Advanced Course. Course participants also prepared an outline Research Proposal”.

**Q 2. What was the take up rate of invitations for the Advanced Course?
Was the class size about right, too big or too small?**

Beginner course: *“There were fifteen applicants all of whom were accepted and thirteen course participants completed the course. The course lasted six weeks with 1 class per week.”*

Recall course: *“There were thirteen applicants, twelve were accepted and all completed the course. The Project Co-ordinator completed the course.”*

Advanced course: *“There were nine applicants of whom 8 were accepted including Self (i.e. the Project Co-ordinator), and all completed the course.”*

“The course numbers were fine i.e. not too many and not too few.”

Q 3. What was your role to manage differences in skills and experiences at the start of the Advanced Training Course?

“Differences in knowledge and skills were accommodated by attendance at the Recall course for which course participants completed a ‘needs and achievement’ form.”

Q 4. How did travel arrangements (distance; transport availability) influence attendance at the Advanced Training Course?

Course participants were from a wide area therefore the Advanced Course was started at 1030h in order to give sufficient time for travel. In the event, there was no evidence of any travel problems, probably because Birmingham has good communication links:

“We also recognised that some course participants may need to get used to regular meetings, and this came into the decision not to start too early”.

Q 5. What was your role in identifying Placement Providers? And what was your role matching course participants to Placements? What changes would you make in the Placement component of the Training Course?

“Finding and agreeing Placements proved quite complicated and took more time than expected. The Project Co-ordinator prepared information packs to send to course participants and then followed them up when necessary.”

Placement Providers were identified by The Service User Development Officer:

“Preparing the Honorary Contracts was frustrating because of the bureaucracy (CRB and Occupational Health checks) that, whilst necessary, took longer than I expected”.

Q 6. What was your role in providing support for course participants in their Placement? And what feedback did you get during the Placement a) from participants b) Placement Providers?

From the beginning of the Advanced Course participants were provided with a named mentor but experience showed that the actual need was small. Advanced Course participants were ‘mature’ and had plenty of life experiences.

Q 7. What, if any, problems or difficulties arise during the Advanced Training course and how did you resolve them?

The Project Co-ordinator explained that initially she was overawed by the brain power on the Steering Group; however this was quickly resolved by the supportive attitudes in the Steering Group:

“At first I felt somewhat intimidated by the seniority of some on the Steering Group because of their qualifications e.g. PhDs, but that feeling soon disappeared”.

Part 3. Outcomes of course

Q 1. What are your thoughts about your role as Project Co-ordinator in the Advanced Training Course? Anything about your role you would like to change? What support did you have to help you in your role?

As with the previous interviews with course participants, Facilitators and Placement Providers, the Project Co-ordinator thoroughly enjoyed the experience. There did not appear to be anything that she would change (but see Part 2 Q 7). Support was from the Steering Group.

Q 2. What was your role in monitoring progress in the Advanced Training Course e.g. course participant satisfaction, and the development of course participant understanding and skills?

Monitoring was by anecdotal feedback from course participants and teaching staff.

Q 3. How do you think the increased knowledge and skills of MH Service Users will contribute to effective participation in Research projects?

Since completion of the Advanced Course, several course participants are taking part in studies where they had their Placement. In addition, the Mental Health Research Network has formed several Groups including a Research Affiliate Group. Separately from the experience gained from the Advanced Course, in the current economic climate the outlook is uncertain e.g. research costing are under pressure and this may limit Service User involvement in research projects.

Q 4. How do you think the Suresearch/HoE MHRN course compares with other training courses for MH Service Users?

The Project Co-ordinator did not have the experience of other training course so could not respond to this question.

Q 5. What was your role in evaluating whether the Course Outcomes met the Course Objectives; and is there anything you would like to change to help the Training Courses evolve?

The Project Co-ordinator commented on the improvements in course participant performance when evaluating the end-of-course presentations of research proposals. Thus the Project Co-ordinator was in agreement with Facilitators, Placement Providers and Course Trainer:

“At the beginning of the Advanced Course, each course participant had prepared a research proposal that was critiqued in a group setting. At the end of the Advanced Course the same proposals were reviewed in the light of the knowledge, understanding and skills gained. This last meeting was a resounding success now that course participants had gained the skills and knowledge to make informed evaluations and to feel comfortable about doing so”.

Q 6. Finally, how will your experience with the Advanced Training Course help to evolve future Training Courses?

Three possibilities were discussed that the Mental Health Research Network, Heart of England Hub)-Suresearch a) tracks the future progress of Advanced Course participants, b) develops methods to identify future training needs for Advanced Course participants once they become involved in research projects and c) takes advantage of the keenness of Advanced Course participants to recommend the Advanced Course to other Mental Health Service Users.

Section 5: Discussion and Conclusions

There was consistent evidence that the Taught and Placement components of the Advanced Course prepared course participants to make an effective contribution as Mental Health Service Users to Mental Health research (*sensu* Hanley B.*et al.* 2009; R Telford *et al.* 2004).

I (Author) have considerable experience of PPI in research projects and in evaluating research proposals e.g. Research for Patient Benefit. There is no doubt in my mind that the standards of knowledge and understanding of the Course Participants were very much higher than those I have observed in many other PPI situations.

Two factors contributed to the excellence of the course participant achievements: 1) the careful preparation of the course strategy and course material and 2) the experience of Mental Health settings by the teaching staff, hence the needs of Mental Health Service Users and the knowledge and skills needed for effective participation in Mental Health research. The understanding and supportive

attitudes of teaching and Placement Providers made a major contribution to course participant progress – the hard evidence being the end-of-course presentations. It was abundantly clear to me that all those involved in the Advanced Course enjoyed the experience – not something that I have always experienced before!

In retrospect, the decisions to arrange interviews at Radclyffe House and to provide questionnaires before the interviews were correct and I would not want to change this in future. The venue was known to interviewees, and provision of the questionnaires in advance of interviews provided opportunities for reflection before the interview.

What I had not anticipated was the effect of participation in the Advanced Course on the morale, self-esteem and self-confidence of course participants. This is something that I think is extremely important and as powerfully commented on by one coursing participant '*The Advanced Course has helped me get my life back*'.

Inclusion of a Placement component in the Advanced Course proved to be very successful as evidenced by all the interviews. Potential pitfalls were the length of time to obtain CRB approvals and the need for Occupational Health Checks for Honorary Contracts suggests that these procedures need to start as soon as possible. Organising and managing Placements depend on what is available and feasible, and the amount of travel in Trusts with extensive coverage.

The aim of the Advanced Course was to increase the pool of Mental Health Service Users and carers for PPI in mental health research studies. The evidence that this objective was achieved is the unanimous agreement between teaching staff and Placement Providers, and that Advanced Course participants are now participating in research projects. By doing so, course participants will further develop their experience i.e. the Advanced Course has the potential for the beginning of a research career. A potential difficulty may be the constraints that the current national financial climate has on funding Research projects and hence the potential for constraints on PPI. On the other hand, the value of PPI in health research, including MH research, is such that inclusion of skilled Service Users and Carers in the research team at the submission stage should favour a successful application and hence contribute to translation of research findings

into practice, an obvious channel being the NIHR Research for Patient Benefit Programme.

Acknowledgements

I would like to thank the Mental Health Research Network, Heart of England Hub for the opportunity to evaluate the Advanced Course and for helping me with the administrative arrangements, and IT matters; all interviewees for being so open and enthusiastic. And I would like to offer a special thank you to the course participants for the privilege of sharing their enthusiasm and professionalism.

Section 6: References

Hanley, B *et al.* (2009). "Public involvement in clinical trials: Supplement to the briefing notes for researchers" INVOLVE, Eastleigh.

Telford R; Jonathan D. Boote JD, 2004. "An evaluation of the process and impact of patient and public involvement in the advisory groups of the UK." *Health Expectations*, **Vol 7**, p209

Section 7: Appendices

Appendix 1: Questionnaires

Evaluation of Suresearch HoE MHRN Advanced Training Course

Interview no: Date Time Telcon or face2face?

Placement Provider

The questionnaire is about the Advanced Training Course Placements and is in three parts: a) the role of Placements in the course, b) Delivery and c) Outcomes of the Placement.

Part 1. Your role of Placements in the Course programme.

1. What difficulties or restraints, if any, have you experienced in the past obtaining effective participation of MH Service Users in Research?
2. What outcomes did you expect a Placement to provide for:
 - a. MH research in general,
 - b. Your Provider organisation, and
 - c. Course participants?
3. Apart from the placement did you make any contributions to the development and delivery of the other parts of the Training Course?

Part 2. Placement Delivery

1. When were you approached about offering a placement for the training course, and how?
2. How many placements were you able to offer?
3. How did you decide what Placement topic to offer?
4. What steps did you take to prepare the research team for the Placement?
5. What, if any, difficulties did participant(s) have attending all Placement sessions?
6. What was your role in providing support for participants in their Placement?
7. What, if any, problems or difficulties arose during the Placement and how did you resolve them?

Part 3. Outcomes of Placement

1. How do you think the Training Course prepared the student to make an effective contribution to research as a Service User representative?
2. Describe the changes in student response during the Placement e.g. interactions with each other and with the research team; making suggestions and asking questions; evidence of learning.

3. Describe how the research team responded to the Placement student.
4. Were there any additional skills that you like to include in future Training Courses?
5. In addition to a Placement can you suggest other ways of Training Course students obtaining practical experience of MH research?
6. Placements were at the end of the Training Course. What do you think about including a Placement at other stages of the Training Course?
7. Have you offered placements to students on other courses for MH Service Users? How did the skills and experience of HoE MHRN students compare with students from other courses?
8. Finally, now that students have received training would you be willing to accept or recommend MH Service users for a research project?

Thank you very much for the opportunity to discuss the Advanced Training Course with you, and for your time.

Andrew Entwistle
25/02/2013 17:43

Evaluation of Suresearch HoE MHRN Beginner and Refresher Training Course

Interview no: Date: Time: Telcon or Face2face

Course Trainer:

Part 1. Objectives, preparation and delivery of Beginner and Refresher Courses?

4. What were the key objectives of the Beginner and Refresher Training Courses?
5. What was your role in inviting service users to take part in the training?
6. How did you decide on the level of training in the
 - a. Beginner course?
 - b. Refresher course?
7. How did you manage differences in student knowledge and skills at the start of

a. The Beginner Course?

b. The Refresher Course?

8. Tell me about the balance between teaching and practical exercises to support the teaching on the Beginner Training Course.

Part 2. Delivery and outcomes of training in the Beginners and Refresher Course.

1. How did you evaluate the development of student knowledge and skills in the Beginner course?
2. What changes did you notice in the level of student's research knowledge and skills?
3. What changes did you notice in the confidence levels of course students?
4. What differences do you think the Beginner and Refresher courses will have on student future contributions to research proposal?
5. When you facilitated the Recall Day following the Advanced Training Day, what effects did you notice on student understanding of Research methods and in the potential for participation as a service user representative?
6. Finally, what other thoughts have you on future courses to train mental health service users to participate in mental health research?

Thank you very much for the opportunity to discuss the Training Course with you and for your time.

Andrew Entwistle

25/02/2013 17:11

Evaluation of Suresearch HoE MHRN Training Courses

Interview no: Date: Time: Telcon or Face2face

Research Project Co-ordinator

The questionnaire is in three parts: 1) Objectives and preparation, 2) Delivery and 3) Outcomes of the Training Courses

Part 1. Objectives and preparation of the Advanced Training Course

9. How did the idea arise for preparing an Advanced Training course for MH Service Users? And what was your role in this?
10. Describe what you wanted the Advanced Training Course to achieve.
11. What was your role as Project Co-ordinator on the Advanced Training Course?
12. Steering Group
 - a. What did you understand was the role of the Steering Group and what was your relationship to it?

b. What, if anything, would you change next time about your relationship with the Steering Group?

13. How was the decision reached to offer the three levels (Beginner; Refresher; Advanced) of training course?

Part 2. Delivery of Courses

1. How were participants selected for the Advanced Training Course and what was your role in the selection process?
2. What was the take up rate of invitations for the Advanced Course? Was the class size about right, too big or too small?
3. What was your role to manage differences in skills and experiences at the start of the Advanced Training Course?
4. How did travel arrangements (distance; transport availability) influence attendance at the Advanced Training Course?
5. What was your role in identifying Placement Providers? And what was your role matching students to Placements? What changes would you make in the Placement component of the Training Course?
6. What was your role in providing support for students in their Placement? And what feedback did you get during the Placement a) from participants b) Placement Providers?
7. What, if any, problems or difficulties arise during the Advanced Training course and how did you resolve them?

Part 3. Outcomes of course

1. What are your thoughts about your role as Project Co-ordinator in the Advanced Training Courses? Anything about your role you would like to change? What support did you have to help you in your role?
2. What was your role in monitoring progress in the Advanced Training Courses e.g. student satisfaction, and the development of student understanding and skills?
3. How do you think the increased knowledge and skills of MH Service Users will contribute to effective participation in Research projects?
4. How do you think the Suresearch/HoE MHRN course compares with other training courses for MH Service Users?
5. What was your role in evaluating whether the Course Outcomes met the Course Objectives; and is there anything you would like to change to help the Training Courses evolve?
6. Finally, how will your experience with the Advanced Training Course might help to evolve future Training Courses?

Thank you very much for the opportunity to discuss the Advanced Training Course with you, and for your time.

Andrew Entwistle

07/03/2013 09:29

Evaluation of Suresearch-HoE MHRN Advanced Training Course

At the end of your Training Course you kindly provided feedback about your experiences of the course. You have now had more time to reflect on your experiences, and we would like you to tell us of any further thoughts. We list questions below to help you reflect on your experiences before the interview.

Part 1: The Training Course

1. Tell us what you understand by the term ‘research’?
2. Why do you think research is important in health research?
3. How can service users and carers help to design a research project?

Part 2: The Research Placement

1. How did the Training Course help in your Placement?
 - a. Tell us how the Training Course helped you to contribute to the research project - e.g. did feel confident to suggest ideas and confident to answer questions?
 - b. Tell us how the Placement helped you gain confidence.
 - c. How did you find others in the Research team respond to your questions and participation?

- d. Now that you have taken part in the Training Programme and Placement, tell me about any other research and/or business opportunities you have been involved in OR how the Training and Placement has helped you look for new research and/or business opportunities?
- e. Tell us about what worked well for you in the Training Course and Placement
- f. Tell us about what didn't work so well and what changes you would like to see in future courses.

Part 3: Summary

1. To round off, would you like to recommend the Course to others and if so particular aspects you liked, and who else do you think would benefit from the Course?
2. What other Training Courses have you attended or are planning to attend? And how do you think they compare with the MHRN/Suresearch Training Course and Placement?

Thank you very much for your time and ideas and we very much look forward to our interview.

Andrew Entwistle/HoE MHRN /Suresearch

Appendix 2: Consent Form

**Mental Health
Research Network**



Consent Form

Thank you for agreeing to participate in the Training Pilot Course in Research Methods
Please tick box

1. I have received and the read the information letter regarding the purpose of this evaluation and was provided with a questionnaire which will form the basis of this interview. I was provided enough time to read the information.
2. I understand I am taking part voluntarily. I agree to the interview being tape recorded and have been informed that all information recorded and produced will be kept confidential (as per Data Protection Act 1998). This information will be returned to the MHRN Heart of England.
3. I understand I am free to withdraw from the evaluation process at any time without giving any reason.
3. I understand that things discussed during the interview and any subsequent follow up contact will be reviewed and a report submitted highlighting the findings. This final report will be published and I have been advised that my anonymity will be protected.
5. I would like a copy of the final report into the evaluation.

.....
Name of Participant Date Signature

.....
.....
Name of Evaluator Date Signature



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