

User engagement in the co-production of knowledge for Knowledge Exchange in Health and Social Care

Project team

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The project

This project involved developing and embedding the co-production of knowledge with service users and carers, transferring expertise and skilled people between the academic, practice and service user/carer communities through partnership working and continuing professional development (CPD). It built on on-going research relationships between CLWR and the SD GP School. Joint studies between CLWR and SD to date have all aimed to identify best practice and disseminate key learning through a partnership approach. Some of these studies were in progress during the lifetime of the project.

The project team has worked closely with SUCIR, which was established in the Faculty in 2009. SUCIR's purpose is to support service user and carer involvement in research in the Faculty. SUCIR's ongoing involvement in this agenda has been invaluable to the project team, particularly in terms of recruitment of all the service user research partners to the project, and advice about payment for them, an issue that remains unclear at UWE.

Key objectives

This initiative addressed five key objectives:

1. User/carer engagement in KE and research to support knowledge co-production.
2. Develop CPD learning and inform wider curriculum development around user engagement in KE, research and the co-production of knowledge.
3. Support bidding for KE and research monies.
4. Relationship building with the Severn Deanery GP school, developing on existing working.
5. Building local networks with other key stakeholders around user engagement.

Progress

Objectives 1, 3 and 4

As part of our working with the SD GP School we engaged two service user research partners (CD, CR), who were invited to become members of an advisory board which oversees the various collaborative studies conducted by staff from both organisations. Two further joint CLWR-SD studies were agreed in the summer of 2010, to be financed by the SD, but due to the impact of the current economic climate, only one is being carried forward, and is currently in progress. Another proposed study formed a component in a larger NIHR bid, led by DE. This bid was successful at the outline stage, and the outcome of our full submission is expected in February 2011. A further bid involving both academic and service user project team members, also led by DE, is being prepared for submission later this month; the outcome of this bid will also be known in February 2011.

The project has identified important learning around service user and carer engagement in research for both organisations. Whilst the research relationship between CLWR and the SD GP School continues, the intention of embedding service user and carer engagement as a routine element of evaluation studies has not been achieved. Some colleagues at SD appear to have embraced the inclusion of service users more readily than others. There was great enthusiasm for service user engagement from the Head of the GP School, who suggested extending the initial plan for service user engagement into an existing SD-UWE KTP project.

Unfortunately, after a few months' collaborative work had already been undertaken by the KTP research associate and one of our service user research partners, it became clear that the SD was not able to grant the latter access to the SD processes which would have been necessary for her to have any meaningful involvement in this project. The key learning emerging from this occurrence is that the concept of service user engagement needs to be fully understood by all professional staff being asked to engage in this way, and the suitability for engagement needs to be clear before investment from service users. Planning for engagement is vital to avoid upset and ensure maximum benefit. Had SD staff been able to attend the CPD events arranged in the project (see below) this would have provided a further learning opportunity for them. Despite a stated intention to have SD representation at these events, it appeared that individuals' workloads prohibited this. Attendance would have enabled the SD staff to think through the philosophy of service user engagement and would have had the potential to address some relevant issues.

One of our service user research partners remains on the CLWR-SD advisory board, and is involved in the ongoing joint research project. However, changes in UWE structures mean that CLWR will soon no longer exist, so it is not clear at present in what form this relationship will be able to continue.

Objectives 2 and 5

Within the project we hosted five CPD events, delivered jointly by UWE academics and service users. Although we initially recruited two service user research partners (CD, CR) to the project, we realised when planning these events that we needed to involve a third service user research partner, and accordingly did so (A-LD). All three

service user research partners were engaged in the project via SUCIR, and have a range of backgrounds, which promotes appreciation of diversity within the project team. The process of jointly planning and running the CPD events resulted in a cohesive project team that worked well together. It is currently planned that all three service user research partners will continue to be closely involved with the dissemination of the project's findings.

The CPD events took the form of a linked series of workshops aimed at service users, carers, practitioners and academics. Three of the five workshops were aimed at all these groups. Additionally, there was one dedicated workshop for service users and carers, and one for academics and practitioners. The workshops were attended by 45 individuals in total: 13 service users and carers, 19 UWE academics and 13 academics or practitioners from other HE and practice organisations. More than half of those attending came to more than one workshop (Table 1). Over the series, 54 evaluation forms were completed, of which 43 were positive/strongly positive (Table 1); the project team were commended for offering what were regarded as groundbreaking and worthwhile events.

Workshop	Numbers attending	Evaluation forms	(Very) Poor	Neutral	(Very) Good
1	24	18	1	3	14
2	19	13	0	4	9
3	9	8	0	1	7
4	9	6	0	1	5
5	14	9	0	1	8
All	75	54	1	10	43

Table 1. Workshop attendees and evaluation forms.

The workshop series produced recommendations for good practice which have been formulated by the project team as guidelines for practitioners and academics (see attached). A leaflet/poster presenting the guidelines is currently being designed and printed, and will be loaded on to the SUCIR website early in 2011.

Attendee numbers

Although the workshop series was successful, we did not manage to attract as many attendees as we would have liked, and nor is the membership of the network quite so large as we would wish. Contributing factors identified have included the difficulty of publicising the events to service users and carers in appropriate fora. In addition, there may have been some problem in sustaining individuals' motivation over the life of the workshop series. We feel that this may have particularly been the case for some of our external academics and practitioners. The dedicated workshop for them was held immediately after the Easter break, when, due to the Icelandic ash cloud, many individuals were stuck abroad, or having to cover for colleagues stuck abroad. There is a strong possibility that this may have contributed to the low attendance for that workshop (as opposed to the numbers actually booked on it), which may have also had a subsequent effect on their attendance at the final workshop. These are issues which the project team will take forward to address for future activities.

Further developments

The workshops yielded a group of 28 individuals (service users, carers, academics and practitioners) who indicated that they wish to be members of a network across health and social care organisations and practice, regional academic institutions and service user organisations. As an initial stage to developing this network, and in order to start streamlining the project work and outcomes with the work that SUCIR is doing in the Faculty, a joint HEIF-SUCIR event was held at the UWE Exhibition and Conference Centre in October 2010. This was attended by 32 individuals of whom roughly half were service users, and the other half were either academics or practitioners. It is planned to continue with these events on a twice-yearly basis, and also to link them in to the project being undertaken by the Bristol-wide consortium which is developing public involvement in research in local NHS organisations.

The team has developed a model of user engagement specified within the guidelines produced collaboratively during the CPD events. PM bid successfully for HEIF funding for 2010/2011 to conduct a project in which the model and the guidelines will be implemented and tested. KP and CR are among the co-applicants for this project. Another service user, who suffers from aphasia after a stroke, was recruited to the team conducting this project following her attendance at the final CPD workshop.

We have been successful with a proposal to run a 90-minute workshop at the annual international research conference hosted by the Royal College of Nursing, to be held in Harrogate in May 2011. This workshop will focus on good practice concerning service user and carer involvement in health and social care research, and will draw on the model and guidelines developed during the project. The workshop will be co-facilitated by five of the team members (PM, CD, A-LD, KP, CR). This is a large conference with an established international attendance, so it will provide a very good opportunity to showcase the work that UWE is doing in terms of public involvement in research in health and social care.

The same five team members are currently involved in preparation of a paper for publication. To support the development of our service user research partners, in November the project funded CD to attend a national conference, Public Engagement in Research, hosted by INVOLVE. The conference offered a range of relevant workshops, including one for service users on developing academic writing skills. CD has produced a report concerning her attendance, providing detail about many of the presentations and about key themes. She found it an interesting experience, which enabled her to get a better understanding of the range of research in which service users and carers are involved, as well as some of the inherent difficulties concerning these types of studies, including the way that varying abilities and qualifications affect presenters' capacity to convey information to a mixed audience. Neither CR nor A-LD were able to attend this conference. Learning from the project will be transferred to develop the undergraduate curriculum through existing KE and research showcase events and other faculty processes. The first of these events is scheduled for February 2011.

KP presented a paper, co-authored by a number of UWE academics, including PM and DE, at the British Medical Sociology Group's annual conference at Durham in September, entitled 'Preconceptions, power and positions: researcher reflections on public involvement in research.' The paper drew on findings and experience from this project and two others which have involved service users and carers.

Service user engagement in research and KE

The collaboration with the Deanery and the workshop series have produced valuable learning about processes and models to support service user and carer engagement in KE, research and knowledge co-production. We have used the learning to produce our model of engagement, as specified within our guidelines concerning good practice in this area.

One recommendation that has arisen from the workshops is that organisations that are serious about involving service users and carers in research and KE need to have processes in place that support such involvement on an ongoing basis; it is neither practical nor realistic to attempt to try to establish them each time a new project is planned. It is gratifying to realise that through SUCIR, the Faculty is already working this way to a large extent.

Another key learning point concerns the time required for professionals to understand the concept of service user/carers engagement in research, if it is to be implemented in any meaningful way. Our experience in this project has made it clear that dedicated time needs to be built into a project plan in order to work through what service user engagement will actually entail in a particular study. Although individuals may express willingness and commitment to involve service users in research, this does not necessarily mean that they have either the skills or the capacity to do so.

It should also be recognised that, should service users be invited to join projects with professionals who do not have a clear understanding of what meaningful service user engagement involves, there is potential for disturbance and/or distress being caused to these individuals. It would therefore appear to be prudent for researchers to consider the likelihood of such eventualities before asking service users to become research partners in projects which depend on staff from external organisations.

Reflections on engagement in the project

We asked our service user research partners to reflect on their engagement in the project, which, it is hoped, will go to inform a paper for publication. Their responses were mainly positive, with some reservations, particularly with regard to the experience concerning the SD-UWE KTP project. There was also a perception from one service user research partner that her attendance at the SD Advisory Board meeting constituted no more than a token presence. However, the second service user research partner felt she learnt from her engagement and enjoyed the experience. Due to the factors outlined above, we do not think that the UWE members of the project team could have done anything more to achieve a better outcome in this regard.

Positive points expressed by our service user research partners included:

- being given the opportunity to learn and to try out new skills, for example, co-facilitating groups;
- having the chance to be regarded as a normal individual again, rather than as someone with a medical condition;
- being given the opportunity to contribute to the shaping of the workshop series;
- having the chance to work with other individuals from a range of backgrounds;
- the trouble taken by the academics to accommodate everyone's needs;
- the openness and inclusiveness of the project team as a whole.

In the wider context, there was appreciation expressed that professionals attending the workshops appeared to be genuinely interested in public involvement in research; that mixing service users with professionals in these events forced each group to listen to the other's viewpoint; and that this particular project is contributing positively to the broader issue of public involvement in health and social care research.

There were obviously also areas where it was felt that improvement is needed. Two of our service user research partners suggested that planning meetings sometimes could have been more focused. One of the team also thought that the academics were on occasions almost too consultative, trying to involve everyone in decision-making for which she did not necessarily feel qualified. However, she acknowledged the difficulty of achieving optimum balance in this regard. There were also some problems noted with facilitation in a very few of the workshop groups, where it was felt that the academics involved did not create sufficient space for input from service users and carers. This is something that we will take forward to discuss with members of SUCIR and other colleagues in the Faculty, as appropriate, in order to raise more awareness of this issue among academic staff.

From the academics' point of view, working with our service user research partners has been an enjoyable process which has also involved a steep learning curve about relevant issues. We have continually had to challenge our own preconceptions about what service user and carer engagement in research actually entails. Consequently, we feel that, through the project, we have gained a much better understanding of all the issues involved. The project has also raised UWE's profile with regard to public involvement in research, both locally and nationally. This can only enhance UWE's reputation in this area, which is gaining increasing importance within the conduct of health and social care research.