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The UCLan Community Engagement and Service User Support (Comensus) project:

Valuing authenticity, making space for emergence

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Abstract

Objective: To develop and evaluate service user, carer, and community involvement in health and social care education.

Background: Despite the high policy profile of involvement issues, there appear to be no published accounts of schemes that have used a systematic whole-Faculty approach to community engagement in health and social care higher education.

Focus of this paper: the set up and early development of a Faculty-wide community engagement project.

Setting and participants: Staff from the Faculty of Health in one university, local service users and carers and community group project workers, and local NHS and public sector staff.

Design: Participatory action research, including document review, field notes, questionnaires, and interviews.

Analysis: Thematic analysis. The emerging themes were tested by seeking disconfirming data, and through verification with stakeholders.

Results: Prior to the study, there were examples of community engagement in the participating Faculty, but they occurred in specific departments, and scored low on the 'ladder of involvement'. Some previous attempts at engagement were perceived to have failed, resulting in resistance from staff and the community. Despite this, an advisory group was successfully formed, and project framing and development evolved with all stakeholders over the subsequent year. The four themes identified in this phase were: Building accessibility; Being 'proper' service users/carers; Moving from suspicion to trust: mutually respectful partnerships as a basis for sustainable change; and Responses to challenge and emergence.

Conclusions: Successful and sustainable engagement requires authenticity. Many problems and solutions arising from authentic engagement are emergent, and potentially challenging to organisations.

keywords or key phrases: service users, community engagement, authenticity, emergence, professional education, higher education

The UCLan Community Engagement and Service User Support (Comensus) project:

Valuing authenticity, making space for emergence

BACKGROUND

The 1978 Alma-Ata 'Health for All' declaration stated that people had not only a right, but a duty to participate in planning and implementing their care¹. The core values of equity, solidarity, and participation were reconfirmed in the 2005 Health for All update.² Concepts of community engagement, partnership, and social inclusion, have become more visible in health and social care literature^{3 4 5 6 7}. Successive UK governments have noted the need for community and organisational partnership, with significant emphasis on collaboration between agencies^{8 9 10}. In addition to this, the publication of The White Paper, 'Caring for People',¹¹ prompted attention to the involvement of individual service users and carers. More recent authors have acknowledged the expertise of service users and carers in their own conditions, and the unique perspective this can bring to health care^{12 13 14 15}. The underlying rhetoric of working together with a common vision towards a common goal¹⁶ appears to be uncontroversial. The translation of these ideals into practice has been more problematic, and there are very few studies of the impact of individual and community engagement projects on personal or service level outcomes.

If the WHO principles are to be effectively translated into clinical and social care practice, a minimum requirement for educationalists is to ensure that social work and health related courses involve service users/carers in delivery of teaching activities^{17 18 19 20 21}. However, reviews have shown that where involvement is happening, it tends to be one-off projects, and/or department or discipline specific^{22 23}. One exception to this could be the new social work degree, which now must involve service users comprehensively²⁴. However, questions remain about the level and method of such involvement, the extent to which it is systematic, and the impact it has on individuals, communities, and organisations.

In a systematic review of literature in this area, we identified 22 studies, and scored them against the northern centre for mental health *ladder of involvement*²⁵. We also assessed if the located studies were focused on one discipline or care group, or applied across groups. Most were specifically focused, and none were applied across a whole faculty. The ladder of

involvement progresses from level one (no involvement) to level five (partnership). None of the studies scored more than 4 on the ladder, and most scored 2-3.

This paper describes the first phase of a service user, carer, and community engagement action research study that was designed to cross the whole of a university health and social care Faculty.

Reflexive note

The originators of the study, MM and SD, arrived with specific beliefs about individual and community engagement. SD felt engagement should be founded on a genuine desire to hear and facilitate multiple perspectives, based on mutual respect and trust. Her experience of project development had led her to value a hands-off approach to innovation. MM shared this disposition towards organic development and was interested in the idea of user involvement as part of a wider social movement. This interest was born out of previous engagement with self organised mental health service user groups. We held it to be axiomatic that community engagement should be authentic to be sustainable. By 'authentic' we meant '*reliable, trustworthy, ...genuine*'²⁶. We were persuaded that, while we could set longer term goals, an authentic approach required us to step back and allow the form and direction of the project to emerge from interaction between key players and stakeholders.

All Comensus participants are co-creators of the findings of the action research work. For this reason, we have tried to use accessible language in project outputs. Direct comments from Comensus members on the interpretation of data are included.

A note on terminology

There has been wide debate on the use of terms such as 'patient', 'service user', 'consumer', or 'lay participant'^{27 28}. This includes critiques of the subordinate implications of the term 'patient'; the rather passive connotation of 'service user'; the market-driven overtones of 'consumerism'; and denial of personal expertise in the term 'lay'. There appears to be less debate on the term 'carer'. In all cases, there is no recognition of those who need services but who cannot access them, or who choose not to do so. In this paper, we have used service

user/carer in the absence of a better term. Our intention was to include those who do not use any formal services.

Aims

Project development: the specific aims evolved, but were consistently focused on maximising student sensitivity to and competence in service user, carer and community issues, and developing effective partnerships between the university and local communities in educational input, research activity, and strategic decision making.

Research study: to evaluate the effectiveness of the project against the project aims, and to identify generalisable insights from the data

Context

The project is based Preston, in the North West of England. The population is relatively deprived²⁹ and the city has a wide range of community support and pressure groups, covering diverse conditions, needs, and interests. The University gained university status in 1992. The Faculty of Health has 9 departments or centers broadly covering nursing, midwifery, social work, postgraduate medicine, and allied health professionals. It has wide-ranging local, regional, and international clinical and academic links.

Before Comensus began, the importance of collaboration with local communities had been recognized by the Faculty of Health. This led to inclusion of some service users on curriculum planning teams, research bidding teams, and some university committees, and the set up of a Service Users in Research group. There was some existing community partnership working that was well regarded by the collaborators, but these initiatives were isolated to specific areas of interest, where local service user demand had already created an obvious opportunity. These projects had reached level 1-2, and, occasionally, 3, on the ladder of involvement.

METHODS

Participatory action research (PAR)

The development and research phases of the project ran in parallel, through a modified participatory action research model³⁰, with a spiral of iterative cycles of planning-action-observation-reflection-planning³¹. The critical emancipatory theories which provide the philosophical underpinning for PAR suggest that the entire project should be conceived of and run by participants³². We used a modified version since the initial framing was undertaken by the project leads (MM and SD). However, all following work was intended to be participatory and emancipatory. We were open to radical changes if this was seen to be necessary. Given its theoretical and philosophical basis, participatory action research is as much about praxis, or developmental (radical) change, as the production of new, generalisable evidence. In recognition of this, we report and reflect on the development of the project as well as synthesising theoretical insights that may be applicable to engagement initiatives elsewhere.

The study involved progressive cycles of work that were each nested in specific phases of the project. We have termed these meta-cycles. Within each meta-cycle a number of micro-cycles have taken place, as planning-action-observation-reflection-planning occur at the critical moments in each cycle. This paper presents findings from the first meta-cycle, spanning the project set up, the formation of and activities of the stakeholders (Advisory) group, the community launch of the project, and planning and outreach activities linked to recruitment to a planned Community Council (January 2004-February 2005). Data collection methods are summarised in table one.

Insert table one about here

The second meta-cycle, to be reported in a subsequent paper, spans the formation and maturation of the Community Involvement Team (CIT: the term now used for the Council), including service user/carer teaching sessions, and module developments, supported by Comensus (March 2005 -June 2006) . The project is currently in the third metacycle, which comprises the increasing independence of the CIT, and the development of a Social Firm.

Analysis

Data were analysed thematically³³. The practical insights from each micro-cycle were discussed and verified at advisory group meetings prior to collaborative development of the next micro-cycle. To reduce the impact of our prior beliefs on the emerging themes, we consciously looked for any data that might disprove them ('disconfirming data').

Ethics

Ethics approval was sought and obtained from the UCLan Faculty of Health ethics committee.

Results (first meta-cycle)

The first part of this section provides an overview of organisational and structural issues arising from the first meta-cycle. Secondly, we discuss the four themes emerging from the analysis.

Insert figure one about here

Pre-project meetings and recruitment of project staff

Prior to recruiting staff for the project, SD & MM visited the local community to assess reaction to the proposals. The responses were mixed, with strong views expressed by some that previous community engagement requests from the university had led to exploitation of local people. This message was taken very seriously, and underpinned the need for authenticity and fair dealing in our project. As a first step, the interviews for project staff included service users as co-interviewees. They were invited through established community collaborations, existing prior to Comensus. The interviews were viewed very positively by the interviewees. One applicant stated:

It was the best interview ever.... The service users asked challenging questions.... The project seemed so real due to the involvement of service users from the beginning..... All in all it was a friendly, welcoming, relevant, positive experience.

(interviewee, interviewed after appointment to project)

The service users and carers who joined the interview panel also commented positively on the experience. One interview panel participant (MAⁱ) is now a member of the project advisory

ⁱ See acknowledgments for the full names of the Comensus Advisory and CIT members who commented on the paper

group. When asked to reflect on the issues in this paper, he stated that '*community involvement in interviews....brought cultural expertise and an inclusive atmosphere...(and I) ...gained in skills in interviewing*'.

The selection criteria for project staff included their expertise in community engagement, and ideological commitment to authentic service user engagement. A personal history of service user or carer experience was seen as a positive factor.

Set up and evolution of the project stakeholder (advisory) group

Prior to setting up the advisory group, the person appointed to the project coordinator role (EJ) made a series of visits to the local community. This was to find out how we could avoid repeating previous mistakes, and to raise awareness about the opportunity afforded by joining the advisory group. Advisory group and CIT members who commented on this paper all spontaneously observed that this initiative was a significant element in success of the project.

The first advisory group meeting was held in March 2004. Members included community workers, service users, carers, and staff from the university, social services, the local authority, and the NHS. The expertise and personal experience of participants included physical disabilities, mental health problems, HIV/AIDs issues, drug misuse, experiences of being elderly, being carers for disabled children and for relatives, and experiences of domestic violence. Participants also belonged to a range of cultures, faith groups, and other engagement initiatives (such as Patient and Public Involvement forums). Members acted as catalysts into and out of the project. They also tracked relevant developments in national policy, within the university, and the wider community. A subgroup worked on development of and recruitment to the Council, and three members volunteered to join the selection panel for Council members.

The main concerns of the advisory group in its first year are set out in box one. As a consequence of iterative discussion and planning around these issues, a range of solutions were proposed and implemented.

Insert box one about here

As well as problem solving, the group and the project team collaborated on designing a website, that became live in March 2005ⁱⁱ; acted as coordinating link for service user engagement projects taking place across the Faculty and between the Faculty and the community and vice versa; and co-presented at a number of national seminars and conferences. We also had a paper accepted for the first international 'Where's the Patient Voice Conference, which was eventually delivered in Canada jointly with CIT members in November 2005.

Community launch and pre-recruitment open day

The formal launch of the project was held in April 2004. The event was designed by the advisory group and project staff. Apart from providing information about the project, three specific areas for discussion were agreed:

- In which aspects of the Faculty of Health's work should the 'Community Council' be involved?
- How should the 'Community Council' be set up and run?
- How can we find out if the 'Council' is working?

Sixty-nine service users, carers, project staff, and supporters, with a wide range of physical, social, and mental health issues and backgrounds, attended the event.

The main work was undertaken in three workshops, each addressing one of the questions above. The workshops were each run twice with a mix of professionals, advisory group members, project staff, community group workers, and service users and carers. They were facilitated by one project member and one service user/carers. One of the attendees, supported by the facilitators when needed, fed back the results of the workshops to a final plenary session for discussion. The key points arising from the workshops are given in box two.

Insert box 2 about here

Overall the day was deemed a success:

ⁱⁱ <http://www.uclan.ac.uk/facs/health/comensus/index.htm>

"The launch event worked well as many service users did contribute."

(Community group worker, interview)

'... the percentage of service users that attended the launch event...was a good number considering the issues that the voluntary community sector had in the past with the university'

(Community group worker, interview)

The event generated enthusiastic debate in the open question and workshop sessions.

A strong message from the community and the advisory group, was that our term 'Community Council' was not liked. Twenty three alternative suggestions were collected during the launch event. Community Involvement Team (CIT) was overwhelmingly preferred, and adopted.

For the ten months following the launch, the project team and the advisory group worked on various issues arising from the launch event and subsequent community encounters. An open meeting was then held by the advisory group in February 2005 to brief local community members who were considering applying to the council, and to support them in making their application. This meeting was attended by signers for the deaf, and translators, to ensure that attendees had the maximum opportunity to take part effectively. On reading a draft of this paper, one of those who became a CIT member (LC) commented that *'prior to joining, I was wrestling with my conscience about whether to take part or not - this was about independence - (my reluctance) was overcome because of the way it was done - EJ was engaging, warm, friendly, and well-placed in terms of who she knew. She was well-connected throughout the community...from the start, the approach was respectful, but especially respectful of peoples independence'*.

Thematic analysis of the first meta-cycle

Analysis of the multiple data sets, and formal and informal reflection on the first meta-cycle generated four themes at this stage of the work:

- Building accessibility
- Being 'proper' service users/carers
- Moving from suspicion to trust: mutually respectful partnerships as a basis for sustainable change
- Responses to challenge and emergence

Building accessibility

The policy literature on accessibility tends to focus on technical aspects, such as opening times, languages used, and the benefits of using a range of media³⁴. Our findings do illustrate the need for awareness of and action in the technical aspects of access, but they also offer some more subtle insights, both about intra-community access, and about the need to balance apparently competing access needs in the case of a wide-ranging community engagement project. Two subthemes were identified in this area:

Gatekeeping

It became clear early on in the project that our aim to involve a wide range of health and social care groups, and both service users and carers, demanded a significant investment of time and energy, especially in the light of expressed disquiet with the image of the university in this regard. We were helped in this by contacts and relationships we already had with established groups (such as a mental health user forum). We therefore had a reasonable insight into key local players; one strategy for building trust was to spend time with some of these people prior to setting up the advisory group:

Physically visiting people prior to the launch event was essential and proved to be beneficial in terms of the groups that attended. It was imperative to contact key gatekeepers in terms of giving the project a better chance.

(Project staff member, interview)

Many members of the voluntary/community sector already knew that the project coordinator was passionate about involvement and this gave her credibility. However very difficult questions were still asked, and justification had to be given for all decisions made. In some cases, the strategies used by gatekeepers were unexpected. For example, one worker reported that she had consciously not brought any challenging service users to the launch event. It is not clear whether this was to protect the service users from the university, or vice versa - or, indeed, both. However, even if this was a benign move, it raised questions about who controls access rights:

"Do certain gatekeepers think that only they can have access to service users?"

(Project team member, interview)

Going the extra mile: maximising accessibility

Both the launch event and the pre-recruitment open session raised issues of accessibility, specifically in the context of the wide and diverse range of those involved. The project team were well aware of the complexities of accessibility, and most team members had worked with groups of people with specific needs. However, none of the team had set up open events where a wide range of needs were anticipated, but where there was no certainty about what these would be. Time and resources became a major constraint:

"There were difficulties to recruit signers/interpreters due to the fact that they are in such great demand and such short supply."

(Project team member, interview data)

Despite the significant attempts of the project team and advisory group to make the event materials accessible, feedback suggested that more pictures and simpler language were needed for Comensus materials.

"The packs were not accessible to service users."

(Community group worker, interview)

It was also reported to be a challenge within certain workshops to enable service users and carers to voice their opinions and to speak freely, given the mix of attendees:

"I was concerned that dual hat users/professionals may be feeding information as professionals and not with their service user hat."

(Community group worker, interview)

Despite this criticism, views from participants after the event, and accounts in field notes, indicated that, within the workshops themselves, the contribution from service users and carers was significant. This was aided by the use of advocates, a card system for indicating a desire to talk, and opportunities to record attendees views on wall charts if they didn't get an opportunity in the sessions.

The gap between what we thought we had achieved in making the launch event material accessible, and what was required, may be explained by the difference between the nature of the advisory group (largely made up of community group workers and professional staff) and the target group for the CIT who attended the event (local service users and carers). Given the innovative range of the Comensus project, the team was also experiencing problems of integration of access for individuals with a wide variety of needs. While the provision of leaflets in simple language, large font, and with pictures was appealing to some attendees, others found it patronizing. This approach also entailed large quantities of paper, which raised issues of sustainability for some participants. All of these aspects required significant collaborative work during the early months of the CIT, led by the subsequently formed CIT leaflets and languages sub-group, using guidance from MENCAP as a template³⁵. The outcome of this work will be reported in a subsequent paper.

While efforts made in good faith will generate some positive benefits, effective access requires regular field testing, willingness to adapt, and enough humility to accept the fact that these initiatives may still be not quite good enough.

Being 'proper' service users/carers

With regard to the issue of representativeness, (of service users), it was proposed that the term 'service user perspectives' be used to avoid attracting criticism.

(minutes advisory group March 04 point 6.4)

"Advisory Group must make a decision regarding dual hat/single hat individuals in terms of Community council membership ... to have less mainstream people with (more) experience in service use."

(Community group worker, interview)

Challenges to service user involvement on the grounds of representativeness tend to surface underlying power imbalances and resistance, since these are usually made by professionals who themselves are not required to be representative³⁶. Unexpectedly, those involved in Comensus also held a range of sometimes contradictory views on this topic, and the issue of who was a 'genuine' service user was a live one. The data indicated that those involved as service users and carers were exclusively individuals with prolonged personal engagement with the health and social care services. To date, the project has found it hard to engage with those who need services, but do not access them. This issue remains to be addressed in future empirical projects.

Moving from suspicion to trust: Mutually respectful partnerships as a basis for sustainable change

There are three aspects to this theme, encompassing the university, Comensus itself, and the meaning of partnership in this context.

Trust between the university and the community

The University acquires money from bids and does not filter this down to the community....

(Attendee at project launch event: From field notes taken at the project launch)

'The image of the University is that it is 'townies versus students' with the University consuming land and buildings'

(Attendee at launch event –later CIT member)

The report of a recent ESRC community engagement workshop records anecdotes of suspicion between universities and their local communities³⁷, and other authors have formally noted this phenomenon.³⁹ Given the specific insights from pre-project visits undertaken by SD and MM, an opportunity was given at the start of the launch event for attendees to

express suspicions and previous disappointments. Some felt this approach set the wrong tone, but others felt that the provision of this opportunity suggested that the university recognised its previous mistakes, and was genuinely committed to improvement, and that this was a prime strength throughout the open community events. Indeed, the events themselves were seen as an indication of good will. One service user who became a member of the CIT (LC) commented on reading an early draft of this paper that *'the whole experience of recruitment was inclusive, welcoming to the university, and user friendly.'*

The approach taken to build mutual trust was through personal relationships - visiting individuals and organisations, exposing oneself, the project and the university to critique, hearing the community stories, and requesting ideas for solutions. As a consequence, one respondent was moved to comment at the end of the launch that:

'I honestly can say I trust the University now.'

(Service user, interview data)

Intra-group trust

The project team was very conscious of how fragile trust can be, and expected to have to continue to work at building relationships between the university and the local community. However, at least, one member of the team was surprised at the intra-group tensions between some of those on the advisory group:

I realised that I had expectations of the service users and carers (that they would be) aware of and sensitive to other service users and carers....

(project team member, interview)

This belief that those who were engaging with the project from the local community were a uniform and politically correct 'Other' was over-simplistic. As one of the CIT members who commented on an early draft of this paper noted (JV) *'I've been involved in lots of things where people get together for a variety of reasons, and people who are very knowledgeable in their own area often seem quite competitive regarding each other - it might just be human nature.'*

Stereotyping those who participate in community engagement as universally (and impossibly) altruistic and mutually trustful ran the risk of limiting understanding of the input needed to build partnerships within the collaborating groups, as well as between the project team and those groups. Later interviews with project staff suggested an appreciation of what was in common within and between the community participants and the university staff:

I think that one of the most pleasing things for me, and it has been a bit of an eye opener, is that there has been so much of what you might call the user experience that is common across all of those different and diverse perspectives.....

(Project team member, interview)

The power of partnership

Arguably, the insights and actions arising from these first microcycles contributed to the early development of trustful relationships and effective partnerships in the CIT. As a CIT member JV commented on reading a draft of the paper: *'people meeting on the CIT were from the very beginning open to each other, and they identified with concern to each other, so these tensions never arose...(this) bonded the group, and helped it to grow harmoniously'.*

Partnership is usually seen as being obviously worthwhile and mutually beneficial to those involved, although there is little formal evidence to support this³⁹. The literature in this area ranges from philosophical debates⁴⁰, to guidance documents on how to do partnership well^{41 42}. One of the key attributes in this literature is the need for authentic relationships. As Bamford noted⁴¹, partners work together willingly and from choice; they promote the partnership beyond the interests of each collaborating individual or group; they are prepared to submerge some aspects of their individuality for the good of the partnership as a whole; they support the partnership in developing a life and identity of its own; they share a belief in equality between the group members, and they put that belief into practice.

The Employers Organisation for Local Government includes some of these aspects in their document on partnership but adds the concepts of 'trust' and 'integrity'⁴². Within the Comensus project the majority of individuals, service users, carers, and project staff did not know each other prior to coming together for the project. As Watson notes, prospective partners may be dubious about each others' motives, and this risk is accentuated in situations

where previous attempts at partnership have wholly or partially failed⁴³. For Comensus, the need for authentic engagement and for the development of mutual trust became even more of an imperative after our discovery of residual resentment following previous attempts at engagement. This experience is likely to be repeated in the interface between many organisations and communities across the UK.

Responses to challenge and emergence

In the context of user involvement, the university holds (and is perceived to hold) significant power. Even if individuals within the institution may be motivated to relinquish some of this, they will face both internal and external resistance. The unconscious processes used by individuals and organisations to maintain their powerbase can lead to marginalisation of service users and carers⁴⁴. Authentic engagement is likely to lead to emergent and unforeseen consequences that may take the process into different areas than those that were planned at the outset. This is not always easy to accommodate in institutions which are based on hierarchies and target setting.

Our approach to the need for flexibility in the development of the Comensus project was to consciously make space for emergence. We understood the concept in terms of complexity theory. This offers one way of understanding dynamic self-organising systems, which evolve in sometimes unexpected directions⁴⁵. As Suchman notes⁴⁶, *'As patterns of meaning and relating are continually re-enacted...new patterns may arise spontaneously...the emergence of social patterns...is a self-organising process; the patterns form spontaneously without anyone's intention or direction..'* (p 41)

A number of organisational issues, including payments to participants, accessing premises and computer systems, having accessible car parking, and difficulties with room bookings, illustrated the challenges of working at the intersection between bureaucracies and emergent ways of working. The territory was complex and the internal and external rules were not always helpful, especially in the area of payment for contributions.

Constructive engagement and dialogue has resulted in a number of supportive developments. More often than not, however, this has had to proceed initially with a degree of consciousness raising within the university beurocracy, and explanation of why the status quo would not be sufficient for our needs. We are also aware that some of our solutions remain

imperfect, and require continuing attention. The potential friction arising at the junction between closed and open organisational systems provides challenges for the effective parallel operation of both in the context of engagement initiatives.

Synthesis

Social movement theories provide insight into why our attention to relationships and emergence was effective in building mutual trust^{47 48}. In this literature, issues of motivation and identity are emphasised, and there is a trend towards collectivist forms of organisation. Arguably, this moves beyond the instrumentalism and rationality inherent in organisational arrangements associated with modern capitalistic societies^{49 50}. This can provide a profound challenge to highly centralised organisations. The first meta-cycle of Comensus has illustrated that an authentic openness to such a challenge can generate valuable dividends. The analysis of the second cycle of data collection will offer more insights into this area, as the project moves from a dominant policy-led engagement to the more diffuse engagement model of the CIT.

CONCLUSION

We have reported on the issues and challenges in developing a system-wide approach to community engagement. The shift to service user and carer partnerships requires broad vision, ongoing communication among all involved parties, dedication, patience, and an authentic desire to move away from comfortable and established patterns of engagement. All partners must be realistic and aim for what can be achieved, while allowing space for unexpected developments. The first meta-cycle of the Comensus Project has demonstrated that systematic integrated systems of involvement can work if they are founded on authenticity and trust, and if they accept and work with the dynamism and emergence inherent in such innovations.

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Table one: Action research meta-cycle one: *Planned activities and data collection*

Phase	Activity	Questions	Tools for data collection
1: Planning	Deciding on initial structure	Who decided how the project should be framed initially? What principles underpinned this approach?	Project notes & bid documents Interviews with project originators
	Appointing staff	How were staff appointed?	Description of interview team and approach to interviews Interviews with staff
	Planning the advisory group	How was the constitution of the group, the location for the meeting, and the membership decided?	Notes/dates of planning meetings. Field notes
		How did advisory group members feel about these issues?	Interviews with project staff Minutes, audiotapes, & field notes from initial meeting
	Planning project launch	How was the location for the launch meeting, the structure of the event, and the invitee list decided?	Notes of meetings Field notes
	Planning the Council	How was the constitution of the group, the location for the meeting, and the membership decided? How was the recruitment process designed?	Interviews with project staff Notes of planning meetings, launch event, and pre-recruitment open day. Minutes, audiotapes, field notes from advisory group meetings Interviews with project staff
2/3 Action/ observation	Running advisory groups	Who attended? How did attendees feel about attending? What was achieved? Successes and problems in set up and running group	Minutes, audiotapes, and field notes from meetings Interviews with project staff
	Running launch event	Who came? Who didn't come? Successes and problems in set up and running event	Field notes from launch Project notes from launch Interviews with staff members and service user worker facilitators
4 Reflection	On the initial scope of the project	Was it appropriate? What were the successes/problems? How inclusive has the action research been?	Minutes and audiotapes of advisory group meetings, field notes and attendees accounts from launch and launch report, interviews with project staff
	On the project design	Expectations, views, experiences of project staff in cycle one	Interviews with project staff
	On the advisory group	Views of advisory group Project staff views What were the key decisions made?	Minutes and audiotapes of advisory group meetings, field notes and attendees accounts from launch and launch report, interviews with staff members
	On the launch	Project staff views Views of participants What were the key decisions made?	Field notes from launch Interviews with staff members Launch evaluation sheets

WHAT NEEDS TO BE CHANGED IN NEXT META-CYCLE?

Box one: Issues and solutions

Issues	Solutions
<i>Representativeness</i> Discussion about the relative contribution of community organisation workers, individual service users and carers, and professionals	There would not be any expectation of representativeness from individual members of the CIT. They would be free to bring forward collective views, eg if they had affiliations to a wider group, but this would not be insisted upon. Individual experiences were to be valued. Workers from community groups/statutory sector organisations expected to bring institutional perspectives.
<i>Payments</i> Rates for payment and methods of accessing expenses and payment, especially for those on state benefits	Service users: All individuals to be offered confidential welfare rights advice prior to accepting monies from the project. All out of pocket expenses (including for travel, subsistence, substitute carers etc) paid in full, typically in cash. For CIT business: Monthly reimbursement of £35 unreceipted expenses, reflecting the demands placed upon participants in the project (cheques via university payroll). This amount can be paid directly to a local community group if people wish, or individuals can choose not to claim altogether. Discrete contributions over and above routine CIT work (teaching sessions, research consultancies) are agreed with particular budget holders. Advisory group members from voluntary sector receive £50 per meeting attended in compensation for their time, paid to the organisation not the individuals. All other AG members are not paid anything.
<i>Inclusion</i> Issues around inclusion, such as the language used, the presentation of documents and minutes (font size, pictures, style	For launch event: supporters for service user attendees; post-it notes for people (or their supporters) to write down things they didn't feel able to say; the use of cards that could be held up to stop the conversation if someone wanted to say something. Flip charts were left on walls. Font for all documents: courier 12pt, double spaced, use of pictures, simple language
<i>Redirection of resources</i> The re-direction of resources to the community, for example in terms of meeting venues and provision of refreshments	There is a commitment to share meetings between community venues and university rooms. When meetings are in the community local groups provide the catering. Big events, Summer Fairs for instance, are held in the community and any monies raised are redistributed back to the community. Relevant training for the CIT was to be purchased from appropriate community sources.
<i>Complementary expertise</i> The need to recognise complementary expertise between all the participating individuals	Participants from all backgrounds have different starting levels of confidence and different talents and expertise. Support, training and capacity building was provided. Resources to this effect within the AG were mobilised by the construction of a skills database identifying individuals and groups associated with specific forms of expertise.
<i>Management of meetings</i> Need to run meetings to time, respect outside commitments, & allow space for all to speak	Chair of meeting gradually taken over by advisory group (and later CIT) members. Agenda agreed by all in advance. System of yellow and red cards used to indicate when people wanted to speak. Agreement about the need to balance everyones opportunity to speak with the need to finish on time.

Box two: responses from Comensus Launch Event

What should the Council be involved in?	How should it be set up and run?	How can we find out if it is working?
Planning, checking and providing teaching and training in the University and the community	Members are to be anyone who has used health and social care services. They should be found by going out to groups and/or having a bigger event	The project/social firm exists as a good, well-known & copied model.
Contribution to all parts of research to make sure that the work belongs as much to service users as to University researchers	People should be on the 'Council' for 1 or 2 years	People should feel that they are supported, equal partners whose skills and job chances are better for taking part.
Contributing to course and Faculty development by being part of making choices and linking with communities	'Council' members are to be responsible for reaching out from their own groups, making sure that everybody uses everyday language and signing-up to a mission statement	There should be better health and social care services, planned and provided by people who are more suitably educated.
	'Council' should hold meetings every 2 months at first, then every 3 months. At these meetings people should share the work so that only one task is done by one person. They should also work as a focus group	Everyday language is used by all and that the project is not just about the issues of 1 or 2 user-groups
	Meet in community settings and at the right time for members. They would also need clerical support, training, respite care for carer-members, information in everyday language, buddies and support from Faculty of Health staff at all level	The number of people who have been trained and employed because of the project, and the amount of service-user input should also be counted.
		Knowledge of the project, use of the 'Council' by the Faculty and taking-on of ideas by other Faculties should also be measured
		The people to ask if the 'Council' is working should include service users and 'Council' members, students and teachers, Comensus workers (including the Advisory Group), people in the community and service providers (statutory and voluntary community)

Figure one: Chronology of Comensus project: first meta cycle

Dates of meetings and other significant events	Other emergent activities
<i>Project agreed by university</i> Summer 2003	
<i>Pre-project meetings with local community groups</i> Autumn 2003	
<i>Recruitment of project staff</i> Winter 2003	
<i>Staff appointed:</i> Coordinator, F/T Jan 2004 Admin support P/T 0.5 March 2004 Research assistant 0.4 March 2004	
<i>First advisory group meeting</i> March 2004	
<i>Community launch event</i> 22 April 2004	Mapping of extent of current user and carer involvement in Faculty activity completed and reported July 2004
<i>Call for members for CIT</i> January 2005	Leicester 4 th National Involve conference November 2004
<i>Open meeting re CIT</i> 8 February 2005	Vancouver conference abstract submitted Feb 2005
<i>Selection meeting for CIT recruits</i> February 2005	Faculty Away Day. To promote project with academic staff, seek additional involvement, and trouble shoot any challenges or resistance. February 2005
	Invited to present at opening lecture at David Brandon memorial event February 2005
	Website live March 2005
	Contribution to other networks: Comensus cited as a nationally significant example of best practice in the published output of a national HEFCE project for Mental Health in Higher Education, in partnership with NIMHE and Trent WDC http://www.mhhe.ltsn.ac.uk/guides/guide1.asp
	Founding membership of DUCIE network - for facilitators of user involvement initiatives in HEIs
	Extensive attendance and participation in various community events and meetings of affiliated voluntary sector groups. Contributions to community newsletters. Support for community group's grant acquisition activity.