Public Engagement in a University Context

The Comensus Program

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Executive Summary

This case study focuses on the work of a service user/carer led initiative called Comensus. It spotlights its involvement in research activities in a Higher Education Institute in the UK. The case study focuses on many aspects of service user and carer research and comments on these activities in relation to accepted models of engagement.

The main points of the report are as follows:

- Whilst public participation in research has increasingly become a demand of government policy, service user involvement in university research is rare. Comensus, in its 11th year, is one of the few higher education initiatives that provides systematic support for service user involvement in university research.
- Service user engagement is valuable, as it can increase the relevance and quality of any research produced, and make a positive impact on the students' experience in the higher education setting.
- Within service user involvement, it is important to minimize real or perceived power imbalances between researchers and service users as much as possible.
- The individual motivation for service users to engage with researchers is primarily a desire to improve experiences in services.
- When services are improved through user involvement in research, service users can be observed to take more responsibility for their behaviour and progress.
- Comensus can be regarded as an initiative of "Responsible Research and Innovation", as it ensures that "*societal actors work together during the whole research and innovation process*" by facilitating the collaboration of university researchers, hospital and social care staff and service users.
- Being involved in research, *"gives me a sense of fulfillment, I feel like I am doing something positive in my life"* is how a service user describes his contribution to research.
- Sustained institutional support is essential for service user initiatives in universities.

Field of Research or Industry

The UK National Health Service (NHS) provides government funded medical care (mostly) free to UK citizens and residents. Universities continue to engage in a "virtuous partnership" (Universities UK 2012, 5) with public health and social care providers, in order to provide the NHS with research evidence and to include practice-based learning in professional education.

During the early 21st Century the development of increased public participation in both university education and research merged with a broader trend in UK Government policy for including the public in the governance and delivery of national and local services, not least within health and social care (DH 2004, DH 2005, HM Government 2007).

At the same time, the public have become more valued within research that informs professional practice, not only as producers of clinical / experiential knowledge but as active contributors to and partners in research (see Church 2005, Hanley 2005, Frankham 2009, Involve 2014). As such, there is an increasing requirement for high quality research to reflect service user, carer or public involvement at all stages of the research process. This is supported

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by government policy and best practice guidelines, and is typically assessed during various research grant awarding processes. Some excellent examples of user-led research are the *Shaping Our Lives* initiative[2] (and the *SURE* group (Service User Research Enterprise) led by Diana Rose at the Institute of Psychiatry[3]. Other initiatives place more of an emphasis upon forging and maintaining positive alliances between academic researchers and service users or carers; these notably include SUGAR (Service User and Carer Group Advising on Research) at City University, London[4], SURESEARCH (Service users in Research) linked to Birmingham University[5] and our own work within Comensus, at the University of Central Lancashire (UCLan) which is summarized in this report.

The ideal is to achieve completely user-led research, or authentic forms of involvement at all stages of the research process. The reality however is that most health and social care research falls short in this regard, and some projects which claim to be authentic do not stand up to closer examination. Public participation and involvement practices have been placed at the heart of numerous UCLan research strategies, and these efforts have been noted by relevant national Research Excellence Framework (REF) units of return, where they have contributed to the respective IMPACT case studies, as well as narratives detailing the wider university research environment.

Event or Activity

Comensus is a university-based stakeholder engagement initiative, which has been facilitating service user- and carer-led research and teaching for over 10 years. Through *Comensus*, UCLan teaching and research staff can count on the involvement of a vibrant local community of health and social care service users and their carers. Comensus is one of the few higher education initiatives that has been organised to provide systematic support for service user and carer involvement, sustained across the university. The work is unique in the UK in terms of its scope (Downe et al 2007), involving people from a wide range of personal starting points and attempting to organise their contributions to teaching and research across the university's health and social care provision.

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Comensus was formed in 2004. Our first task was to set up a stakeholder community advisory group to work with academic staff on the foundations of the project. It was especially important to design a process for ensuring that the eventual participants would be in a position to shape the development of the project authentically and actively, and not merely adapt to a pre-determined blueprint. This preliminary work involved project framing and development, and involved all stakeholders over the subsequent year. From this work four key themes were identified:

1. **ensuring accessibility**;
2. **being 'proper' service users/carers – the issue of representativeness**. Within the project this referred to
   a. who the service user/carer group themselves defined as service users and carers, and
   b. the use of the concept of representativeness by some health and social care professionals to resist such involvement;

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2 http://www.shapingourlives.org.uk
3 http://www.kcl.ac.uk/ioppn/depts/hspr/research/ciemh/sure/index.aspx
4 https://blogs.city.ac.uk/sugar
5 http://www.suresearch.org.uk

3. **moving from suspicion to trust** - this theme acknowledged that at the beginning of the project service users and carers were suspicious of the motivation behind the work. Staff built good relationships based on honesty and openness;
4. **mutually respectful partnerships as a basis for sustainable change**; and
5. **responses to challenges and developmental change**.

In the second year of the project, a Community Involvement Team was set up with membership from a wide range of users of services and carers. The success of this was maximized by planned and emergent training and support mechanisms, the provision of time and space to maximize relationships, and the possibility for innovation and mutual support. Two overarching themes were identified in this phase: **Experiences in Comensus**, and **Organising for Action** .The members of the project recognised that once the fundamentals were in place they were ready for the next phase of activity, which for them was to 'make a change' to practice in order to help others to have better care.

Engagement activities

Throughout its 11 year lifespan Comensus has engaged in numerous innovative engagement activities. These have included inviting people 'who have used' or 'care for those who have used' health and social care services into the university to contribute to teaching, research, and input into strategic decision making. **This enables the voices of service users and carers to be heard and valued, with the aim of improving the relevance and quality of any research produced, and make a positive impact on the students' scholarly experience.**

WHY DO WE DO IT?

The members of *Comensus* have signed up to an ethos which holds that the research the university carries out cannot be delivered effectively without involving stakeholders. We believe it is impossible to appreciate from only a book or other traditional means of learning and research all of the emotional nuances of what it is like to be a recipient of care, probably in distress, pain or anguish and possibly feeling frightened and lonely. These unique insights should be used positively to influence the design and development of future health and social care research.

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Comensus members also feel that it is not only the involvement of service users and carers in research that is important but also the scope and foci of activity that is vital. Often, service users and carers are asked to contribute to research that has already been defined by funders, professional bodies, academics and researchers. However, **service users and carers want to go beyond this tokenistic involvement by being strategically involved in all aspects of activity from definition to completion of activity.**

When working together very closely however, some difficulties can occur. For instance, when students and researchers have an opportunity to meet service users and carers, they are expected to conduct themselves 'professionally' and maintain the implicit interpersonal boundaries that a 'professional' identity usually entails. These boundaries sometimes mean that it would be deemed inappropriate to build alliances that go beyond the foci of research and become perhaps therapeutic relationships or a vehicle for friendships to be built. As such, it is important that a safe and supportive environment is provided in which researchers, service users and carers can collectively reflect upon experiential

aspects of health and social care together. This helps to minimize real or perceived power imbalances between researchers and service users.

In our experience, service users and carers are often very keen to ensure that their input is valued as a legitimate form of knowledge, and that it is therefore used practically to improve research.

Comensus members recognise that there are dominant structures for research and that it is imperative that all of the organisations concerned not only aspire to working in partnership with service users and carers, but understand that this should occur through an ongoing radical agenda of greater power sharing through co-productive activity.

Picture: Comensus members[6]

HOW DO WE DO IT

Comensus participants are involved in three broad and inter-linked domains of activity: teaching, research, and strategic development across the university. None of these are completely independent of each other. For instance, there is a commitment through the research-informed teaching agenda to reflect more fully research in teaching. Hence, academic staff who have been involved in research projects are able to bring this experience into their teaching, and illustrate various learning objectives with examples of research findings that have been drawn from user-involved research studies. A Comensus working group has recently been engaged in critical thinking about how the Schools responsible for health and social care at Uclan can best develop a more appropriate infrastructure to support service user and carer involvement in their research programmes.

The strategic work also extends to discussion, debate and influence over the university's support for research, particularly in the context of user involvement. The nature of Comensus as a community engagement initiative means it is well placed to support the wider university mission for public engagement, which undoubtedly enhances matters of knowledge transfer, research visibility and impact. Indeed, Comensus is increasingly recognised as a significant university resource, for example in the 2014 REF submission.

Examples of Engagement Activities

Comensus hosts a bi-annual international conference – 'Authenticity into Action'. The conference, including the theme, the call for abstracts, and the organisation and delivery is the remit of the service users and carers of Comensus. **This is the only UK conference initiative that focuses solely on service user and carer involvement in higher education**. The conference encourages service users and carers to present their work and welcomes new presenters. The conference also offers free bursary places

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[6] Consent for the inclusion of images has been obtained.

to service users and carers. The organisation of the conference is a model of good practice in that the abstracts and the bursary decisions are made by service users and carers from similar initiatives within other HEI's within the UK.

MENTAL HEALTH - IT'S EVERYBODY'S BUSINESS

The international film festival 'One in Four' is hosted by the project annually in October to coincide with World Mental Health Day. The primary aim of the Festival is to engage students and the wider community in critical thinking and open debate related to public opinion on mental health, stigma and discrimination. We show a film focusing on a different aspect of mental health each night of the week. An organising committee of service users, carers and students affiliated to Comensus plan and organise the Festival. The highlight of each evening is the introduction to the film by a service user/carer who has experience of the issue presented in the film. This gives a real life insight to the film and provides topics for discussion at a facilitated debate that immediately follows the screening of the film. We have collectively evaluated the impact of the film festival and its pedagogical value. It was important to see that Comensus participants highlight the extent to which filmic depictions of mental health, similar to live service user involvement, touch people at an emotional level and thus are profoundly influential for learning (McKeown et al. 2012, Comensus Writing Collective 2015).

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The film festival also has as its focus a full day that centres on music and creative performance and hosts a market place venue for local community groups to engage with students and discuss their services. A local Community Interest Company (Music and the Mind), a group facilitated by service users, provides musical entertainment in the immediate build up to the films and throughout the community day. These initiatives have been influential in persuading the local City Council to sponsor a series of public events focused upon mental health in 2015, which will hopefully become an annual event.

Whilst Comensus is also heavily involved in making health and social care teaching more relevant to service users, this report focuses on research, as a case study of responsible research and innovation (RRI).

Comensus and Research

Various UCLan research projects have been organised in ways that have made the most of involving service user and carers, with a number of key research personnel supporting this inclusive type of working. Comensus is in the healthy position of being at the centre of a significant network of service users and carers and associated community groups, who have an ongoing interest in engaging in research projects and programmes. These are situated locally, nationally and internationally.

Comensus was conceived as a participatory action research project (Downe et al. 2007, McKeown et al 2010, McKeown, Malihi-Shoja et al. 2012). We found that more often than not **individual**

motivation to be involved with us is primarily driven by a desire to improve experiences in services. Teaching and research involvement opportunities are viewed by service users and carers as stepping stones to achieving better services. We have endeavoured therefore, to render our contributions to research so that they bring maximum value to services and in doing so optimise the extent to which best ideas are taken up in practice. Similarly, Comensus participants are committed to research-informed teaching and so have an interest in connecting inquiry and pedagogy.

It has to be acknowledged that the desire for impactful research is often rooted in service users' and carers' critical perspectives of existing health and social care services. This can sometimes also be related to past failures of statutory services in acknowledging and welcoming the valuable contributions that autonomous service user and carer groups can make.

It is through deliberation on such matters that Comensus has arrived at a process which allows us to engage in decision making and strategic planning processes to take Comensus forward in an operational sense, while simultaneously valuing its members' input. Our processes value difference and different points of view, forcing us to engage with some of the unsettling and unsettled interactions which inevitably arise in the research and teaching context, and elsewhere in Comensus.

Strong institutional support for service user and carer involvement from UCLan is a key factor in supporting our attempts to connect research efforts with university curricula, courses and wider teaching and learning. It should be recognised, however, that involvement in teaching and learning is more thoroughly developed and supported than involvement in research. Research grant acquisition is only a limited means of financing comprehensive involvement, because it usually only occurs on a project by project basis. The involvement that does occur in research projects also tends to be associated with those academic researchers who are already persuaded of the value of involvement and are committed to making it happen. Comensus, its affiliated membership and the community groups it is associated with, therefore offer the advantage of being a standing resource which researchers can draw upon.

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Comensus has also convened its own series of workshops where we met to define research questions. This focus on topics of interest to the group is then shared with academic research teams via established involvement with team meetings and various inter-disciplinary groups. Comensus members are consequently involved in international and national research projects via UCLan. These take many forms, including a project concerned with the reduction of physical restraint in mental health care (Duxbury 2015) which has opened up opportunities to extend Comensus involvement into an established European Violence in Psychiatry Research Group (EViPRG) (http://www.eviprg.eu/). Members are also involved in research around stroke prevention and aftercare, which has already been presented at the international stage, see Jones et al (2008).

Comensus' involvement in teaching, research and writing has led to the contemplation of the ideology and deeper thinking around the potential successes and pitfalls for alliances between critically engaged researchers and autonomous service user groups. This finds its expression with researchers who are active in building alliances through their community engagement work on behalf of the university, their work as trade unionists and their personal support for various user movements. The establishment of Comensus was partly aimed at connecting research with teaching and has provided

for user involvement at all stages of the research process, including helping to define pertinent research questions.

There is a valuable international dimension to this work which has connected to Canadian and US scholars who are affiliated to the *Mad Activism and the Academy* group and who have been invited to present their work at UCLan in recent years. One consequence of this and linked activity has been the recent emergence of a field of *Mad Studies*, a form of critical disability studies. Initiating symposia have been held at Lancaster University and co-organised with UCLan staff, building upon earlier events at UCLan and in Toronto. Associated publications include the seminal Canadian edited text *Mad Matters* (Le Francois et al. 2013), and a review of this (McKeown & Spandler 2013), together with a European adoption of the field (Russo & Beresford 2015). Thinking about involvement in terms of 'movement politics' opens up consideration of the sorts of social space that might support authentic involvement, and the forms of decision making and democracy that might go along with these (McKeown & Jones 2012, McKeown et al 2014, McKeown & Spandler 2015).

Photo: Hans Thoursie

Another development has been researchers attempting to practice different models for bringing collective and individual writing contributions to fruition in a way which properly credits authorship. This has resulted in numerous multi-authored journal publications (Malihi-Shoja et al, 2013, Mckeown et al 2012) and a co-authored book (Mckeown et al, 2012 , with another in production). Similarly, Comensus participants have been involved in research dissemination activity, including through delivery of presentations at national and international conferences. Some of these have been conferences with a specific focus on public engagement in research, while others have simply sought to reflect user involvement in research studies as a theme.

Recently completed research studies have either included a high degree of service user involvement or have made involvement practices their primary focus. One has studied involvement practices at a number of low and medium secure mental health units across the Yorkshire and Humber region (McKeown et al 2012 – more information on the study is also provided below). Comensus is about to start a similar study in a high security hospital in the north-west of England. Our researcher has also been on hand to support an appreciative inquiry project working with mental health practitioner teams to develop new working practices that are relevant to both 'recovery' and user involvement. In addition to the researchers' contributions, all of these projects involve panels of service users that have provided active input into their processes for planning and analysis. Along with the researcher, panel members have received bespoke training that is delivered in the participatory spirit promoted by Freire (1971). In effect, learning is always a two-way process, with the academic facilitators learning a great deal about the talents, interests and experiences of service user participants. This can provide secondary insights into the practical credibility of the research process itself, as well as ensuring participants understand the role of researchers better.

Building upon a symposium which analysed different initiatives for levels of authentic participation, Lathlean and colleagues (2006) offer a representation for a continuum of participation which can be used to benchmark other initiatives. We will use this continuum to portray our research activities. Lathlean's continuum moves along a horizontal plane from the left hand side, where users are passive, to the right hand side, where users lead initiatives.
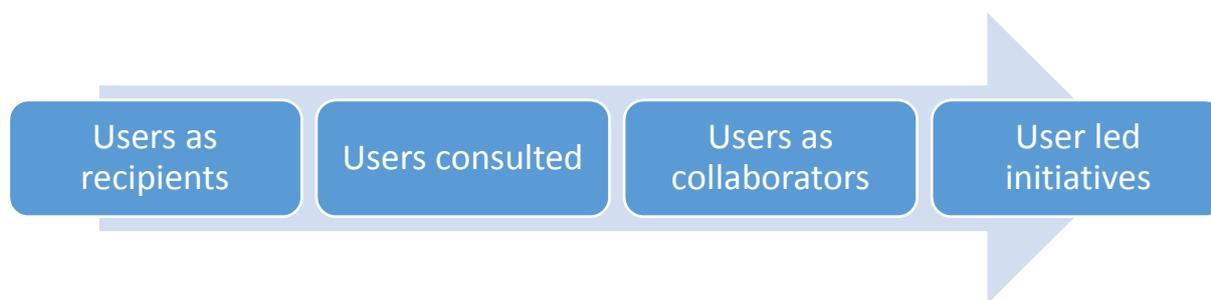
Fig 1. Continuum of participation (services and education), adapted from Lathlean et al (2006) p 734

Examples of involvement in research and related activity

APPRECIATIVE INQUIRY ON TWO MENTAL HEALTH WARDS

This research study applied appreciative inquiry methods to working with the multi-disciplinary teams on two mental health inpatient wards collectively to develop new ways of working. The focus was on innovation to modify working practices to allow more involvement of service users, enhancing their voice in decision-making, and enabling them to take a more active role in their own care and treatment. As such, the greater democratisation of care that was sought reflected the implicit democracy of the chosen participatory approach for conducting the research.

The project was led by academic staff who are closely allied to Comensus, and provides a number of examples of involvement practices. The research was grounded in a prior consultation process where a list of service user defined research priorities were identified. In particular, service users seemed to display an affinity for certain types of methodology, including participatory action research methods. These were seen to privilege democratic decision making and hence offer greater opportunities for authentic participation. Academic researchers supported service users in their preferences and negotiated for funds from NHS budget holders on their behalf.
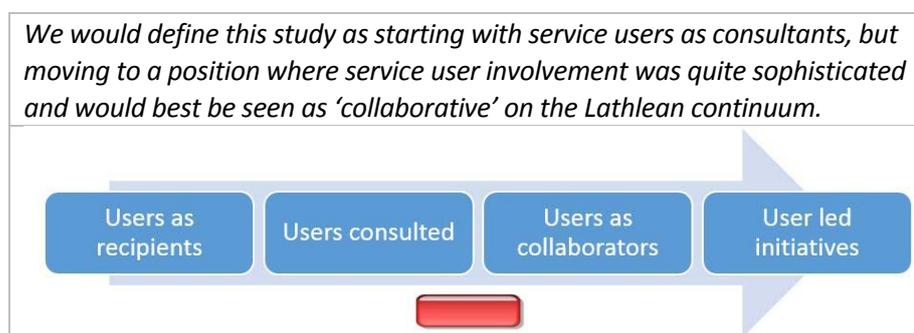
Once funding was agreed, the shape of the project was increasingly defined by the views of Comensus participants. A small sub-group of those with a personal interest in mental health inpatient care was convened, and continued in an advisory capacity for the duration of the project. Project funds were also used to employ a service user researcher in a development post who has since been employed on a number of subsequent projects. Because of the participatory nature of the project, service users residing on hospital wards also became actively involved.

It was anticipated from the outset that the respective ward teams taking part in the project would already be engaged in their own participatory activity and through the action orientation of the research become enthused and motivated further to engage creatively and dynamically with service users residing on the wards they serve. A set of particular objectives for practice change were framed by notions of recovery and involvement. This incremental approach was seen to be a realistic foundation for meeting the longer-term expectation that staff teams would sustain any emergent service user involvement in practice.

Overall, **the study demonstrated a number of positive outcomes on each of the wards where it was present**, including:
- measures to give service users more control over systems for medications management, as well as
- improved connections between ward based and community based activities.

From a critical perspective, the attempt to practice participation and democratise the organisation of ward based work was complicated by previous experiences and preparedness to take on a more active role in strategy and decision making. Interviews with staff participants and ethnographic observations revealed that certain staff were well disposed towards the democratic impulse implicit in the research methods and did their best to capitalise and contribute to creatively formed changes to working practices and ward activities. This was not uniform, however, and some staff actively resisted attempts to encourage a democratisation of their relationships and working practices on the ward. Others were not against it necessarily, but simply unprepared for such democratisation and definitely lacking in the skills or disposition to make the most of participatory opportunities. Some revealed that they had never previously felt that their personal contribution to strategic thinking was likely to be sought or would be valued, and hence maintained a fairly instrumental attitude to their work. In this sense, the service user involvement in the research methods modelled forms of shared decision making that had been hitherto absent from the professional context but were the ultimate objectives of the project:

> *We would define this study as starting with service users as consultants, but moving to a position where service user involvement was quite sophisticated and would best be seen as 'collaborative' on the Lathlean continuum.*

EVALUATING INVOLVEMENT PRACTICES IN SECURE MENTAL HEALTH SERVICES ACROSS THE YORKSHIRE AND HUMBER REGION

This research project was designed around practice case studies. It was first conceived by a Regional Involvement Strategy Group that operates in Yorkshire and Humber, a geographical region in the North East of England. It includes service user and staff representatives from all of the secure mental health units in the region. As such, the invitation to tender for the research contract was initiated by an alliance of service users and staff. In this context, the participants prefer to refer simply to 'involvement', rather than 'service user involvement', reflecting their intention to forge alliances between staff and service users.

We were able to use the project to make constructive links between interested members of Comensus and active service users and staff in Yorkshire, to support our research study. We convened two small groups of service users to contribute to the project over its lifespan - one made up of Comensus members and one locally convened in Yorkshire (UCLan and therefore Comensus is based in neighbouring Lancashire). These groups then discussed emergent issues in the planning and delivery of the project, as well as helping to identify and articulate prominent themes, as part of the analysis of anonymised qualitative data. Because of geography and limited funds for travel, together with certain restrictions due to the Yorkshire group comprising residents of secure units, the two groups did not meet face to face. However, it was possible to maintain effective communication between them. The aforementioned service user researcher post-holder[7] was a member and facilitator of both groups, providing a degree of continuity between them.

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[7] The researcher had personal experience of secure wards.

The project generated the following results.

A key finding about the nature of the involvement practices we studied was around the quality of communication and how this led to changes in practice, as well as changes in attitude to the very idea of involvement in this particular practice context. The best of these practices were found to be dynamically creative and deliberative, and hence highly democratic. This was often in stark contrast to previous experiences for individuals subject to secure care; so much so that we titled one of our subsequent publications: 'It's the talk' (McKeown et al 2014), emphasising the value of democratised communication processes for achieving progressive changes in practice.

Affording more involvement in decision making appeared to be associated with service users taking more responsibility for their behaviour and progress through the system. There were some fairly obvious implications for involvement that were derived directly from distinct features of practice norms in this setting, including the application of physical security measures which could constrain the quality and experience of such initiatives. That said, the period in which these involvement developments were enacted correlated with significant reductions in serious incidents and lower rates of bed occupancy.
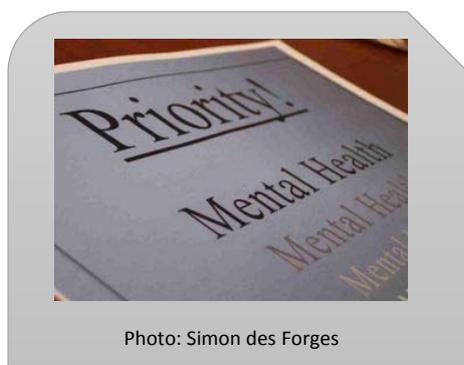

Photo: Simon des Forges

We made sense of these findings with reference to critical debates about deliberative democracy as a vehicle for social change. This opened up interesting collaborative discussions whereby the intuitive sense-making of individuals could be seen to marry up with more theoretical contributions brought to the table by academic researchers. Hence, this could be seen as performing an analysis collaboratively and was reflected in jointly authored papers (McKeown et al 2014).

Ultimately, we would say we have been concerned to practice democratic and deliberative approaches throughout the course of our inquiry methods. This way of working does not necessarily provide an easy road to consensus or convergence. Indeed, they are arguably examples of paradoxical spaces, which contain clashes of different ideas and opinions, or fairly unsettling interactions and communication. The methodological craft we attempted to explore was to harness such differences as a jumping-off place for creativity and constructive thinking. The fact that some such discussions may not have been resolved into a consensus means that we sometimes had to be comfortable with, and able to accommodate, a plurality of positions and possible solutions. In the case of the involvement initiatives in secure units, there is a clear related issue arising from our study. That is, some service users resist the constraining features of secure care to the point that they do not cooperate, even with fairly liberalising initiatives. We hope to engage in further studies of this 'recalcitrance'.

By way of reference to the Lathlean framework, this study was arguably a 'collaboration'. There were, however, features of its initial conception that suggest it was in part 'user-led', because service users made a substantial contribution to the decision to commission a research study of this kind and see that funds were allocated.

RESTRAIN YOURSELF PROJECT

This large national multi-centre study covers 16 mental health wards across the North West of England. The aim is to evaluate whether a system for changing staff practices to reduce levels of physical restraint is effective. Recruitment of participants in research studies is often difficult in the context of mental health wards, where notions of cooperation are undermined by systemic practices of compulsion and coercion. Being able to identify with the person approaching you for recruitment into the study, at least to some extent, appears to be beneficial in supporting these encounters, developing trust between researcher and potential participant. It was therefore invaluable that a member of the academic research team has experience of being a patient on a secure ward.

Similarly, in the planning and supervision of the project, a person who has actually experienced coercive practices, including physical restraint, is invaluable in supporting fellow academic colleagues with making decisions about their choice of which factors to measure and in what way, as well as approaches to matters of ethnography and qualitative interviewing. A classic example from this project relates to a sense amongst the research team that participating staff may be guarded in responding within interviews, reflecting the 'party line' on the use of restraint, rather than being completely honest about their own views or opinions. When meeting to reflect upon this, the service user researcher identified a simple question to pose to staff members on the secure ward: 'Can you tell me about the very first time you had to use physical restraint?' This form of questioning appeared to open up greater veracity in responses and engage with a more emotional account of events.

The scale of this study was and is a step change for the service user researchers. Their work on the wards has been challenging, due to occasional lack of support or even resistance from ward personnel, which particularly affected their ability to offer opportunities to potential participants and recruit them to the study. Such circumstances highlight the necessity for robust systems of personal support for individuals carrying out such work. To this end, we have arranged regular supervisory/advisory contact, and have procedures in place for emergency support should it be needed. Senior research personnel have made time to accompany the more junior researchers for at least one of the days they are on each ward, usually the first day that they attend.

> *This study is a fairly straightforward research project, with many academic partners and collaborating NHS organisations involved. As such, the service user involvement is modest, and largely embodied within the single service user researcher. That said, the contribution of the researcher who has personal experience of secure wards undoubtedly influenced the course of the project positively, meaning that it is perhaps both 'collaborative' and 'user-led'. We would therefore claim elements of 'collaborative' user led activity on the Lathlean continuum.*

| Users as recipients	Users consulted	Users as collaborators	User led initiatives

INVOLVEMENT IN UCLAN HEALTH RESEARCH METHODOLOGY AND IMPLEMENTATION (HERMI) GROUPS
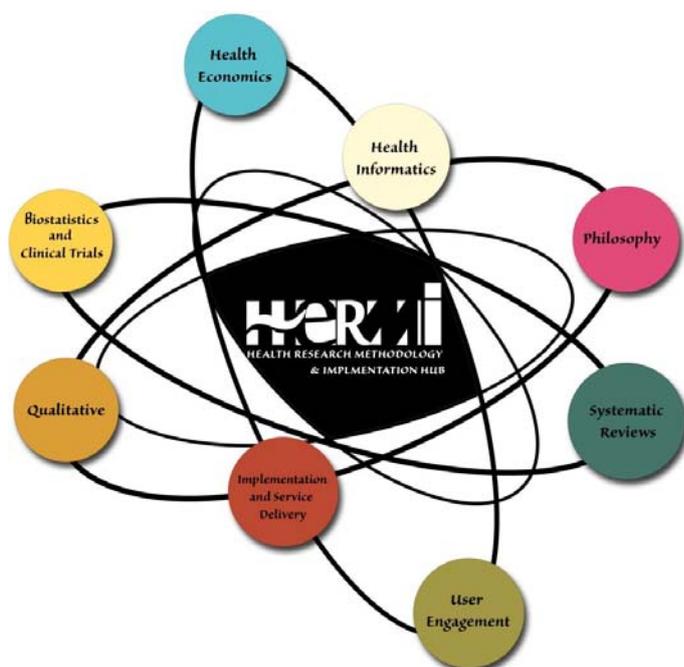
The School of Health at UCLan has developed a variety of Health Research Methodology and Implementation (HERMI) groups under a central umbrella. The groups identify methodological expertise (e.g. systematic review) in a range of research groups (e.g. mental health, stroke, cancer). There is a defined HERMI group for service user and carer involvement in research. Hence, it is currently under discussion whether service users and carers will be involved in meetings for the wider HERMI hub. This involvement is of interest because it concerns a key strategic university function, and brings at least some service users and carers into the orbit of senior researchers, professors and managers. It is, admittedly, limited to a 'consultative' level of input, but can at times be seen to exhibit characteristics of 'collaboration' – especially within smaller sub-groups that have particularly defined objectives.

Largely consultative involvement on the Lathlean continuum at present, but with some opportunities for collaborative alliances.
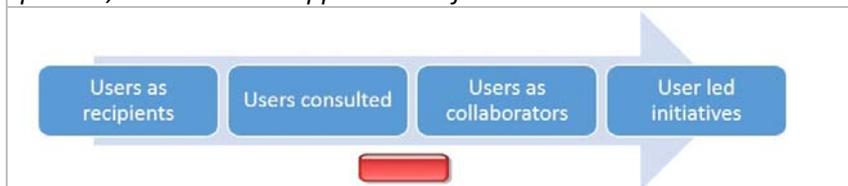
TORONTO LINKS – 'MAD ACTIVISM IN THE ACADEMY'

In the mental health field, we maintain constructive links with colleagues in Ryerson University, Toronto, which has helped our own development significantly. We have attempted to understand the university context in which Comensus is embedded through a social movement lens. In this sense, we see the collective participation of service users and carers as sharing some of the characteristics of social movement activists, who often desire progressive changes to the over-arching practice situation. As such, involvement in research studies may be seen by some as an indirect route to achieving such change. Thinking in this way also opens us up to thinking about the characteristics and attributes of academic personnel, who might be encouraged to support or ally with such initiatives. To this end, we have attempted to develop thinking within Comensus that makes use of social movement and activist theories, considers the notion of 'critically engaged academics' and speaks to broader epistemological critiques of health services and bio-medicine.

These interests and connections then extend into wider critical disability studies. We have collaborated on a number of initiatives under the heading 'mad activism' and relating to an emergent field of 'mad studies'. Our ongoing relationship has involved a number of visits of academic staff and service users in

both directions, typically engaging with international participants from other international universities in the course of specially convened symposia.

> *Through this collaboration, we combined elements of 'consultation' and 'collaboration' around learning that is concerned with being ultimately 'user–led' on the Lathlean continuum.*

Continuous Improvement - Standing Working Group on Research Involvement

Despite the systems for involvement that we already have at our disposal as the means to support involvement in research, we are continually concerned with giving attention to how our systems and practices could be improved. To this end, Comensus has established a standing working group with a specific focus upon research involvement. This group is charged with considering any additional

Working group meeting

development work that might be needed to establish more integrated, systematic and supportive systems; not least in terms of a more systematic approach to training and capacity building for service users wishing to be involved in research projects and programmes.

The group has recently made recommendations to College Heads and the University Director of Research, with regard to the following areas:

General and systemic issues
- the need for detailed work to identify the ideal system for supporting service user and carer involvement in research and how this might be funded sustainably;
- the relationship of current systems, such as Comensus and other networks of service users/carers who have come together on previous projects organised independently of Comensus, and user networks that exist in other universities;
- linking involvement to a wider focus on community engagement;
- further thinking upon collective and individual forms of involvement by learning from practices we are connected to in other universities (City University model is a standing panel who develop user/carer led research ideas, for example);
- linking our developments to our international work to make the most of established international partners;
- exploring how we can best integrate developments within the NHS and national involvement networks;
- improve on our relationships with service provider organisations with regard to service user/carer involvement;

Matters concerned with enhancing institutional support for user/carer involvement
- development of new systems that should adhere to a standard for best practice in payments and expenses for different sorts and levels of involvement;
- recognising that developing a systematic approach, going forward, will require some degree of staffing resource to support involvement in research;
- considering user/carer researchers, research assistants, or models for such personnel being employed by independent voluntary sector groups but engaged in university research;
- devising appropriately tiered training and capacity building practices to accord with the different levels of training of service users/carer for research involvement, capacity building, knowledge and skills for research that might be needed (accredited or otherwise);
- flexible mechanisms whereby service user/carers might access university courses without paying fees or at reduced rates and how this might be offset against other contributions in a quid pro quo arrangement;

Changes to research culture and working practice supporting research
- developing thinking around the fact that it is much easier to support and pay for involvement once a research grant has been secured, rather than in relation to necessarily advanced activities such as bid writing and other research associated core business;
- applying critical thought to different ways in which involvement can be practiced within specific research projects, steering groups, reference panels, user/carer researchers and co-researchers, action research etc.;
- recommending better systems to match professional researchers with interested service users and carers, matching their profiles such as knowledge, skills and interests in a database which can also be used better to reflect their research interests;
- developing service user/carer contributions to project approval, ethics review, and wider research governance;
- developing effective and creative approaches to writing, dissemination, authorship and credit;
- encouraging PhD studentships focused on involvement and participation and also making the case for protected PhD studentships that are designed for service users/carers with built in support and bursaries;

- further developing the new role of service users/carer as advisors, supervisors or examiners for post-graduate studies;

Why does Comensus fall under Responsible Research and Innovation (RRI)?

DEFINITION OF RRI FROM EUROPEAN COMMISSION

RRI is an inclusive approach to research and innovation (R&I), to ensure that societal actors work together during the whole research and innovation process. It aims to better align both the process and outcomes of R&I, with the values, needs and expectations of European society.

In general terms, RRI implies anticipating and assessing potential implications and societal expectations with regard to research and innovation. In practice, RRI consists of designing and implementing R&I policy that will:

1. *engage society more broadly in its research and innovation activities,*
2. *increase access to scientific results,*
3. *ensure gender equality, in both the research process and research content,*
4. *take into account the ethical dimension,*
5. *promote formal and informal science education.* [8]

Engage society	Open access	Gender equality
Ethics	Science education	
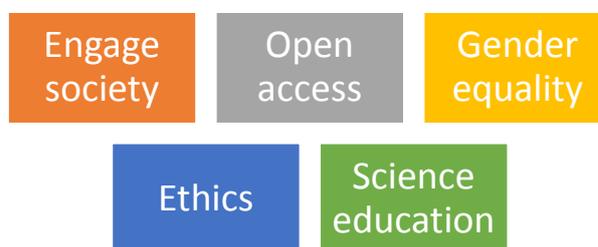
The Comensus initiative falls clearly within the parameters of RRI.
It ensures that "*societal actors work together during the whole research and innovation process*" by facilitating the collaboration of university researchers, hospital and social care staff and service users. As a result, it is possible to align the research process and the research better with "*the values, needs and expectations of … society*". Of the five RRI action points, Comensus works most closely on "*engage society more broadly in its research and innovation activities*", but also increases access to scientific results amongst research users.

Comensus is an innovator in its field and the breadth and scope of its activities reflect this. Comensus opens up opportunities to the broader public around research engagement, research development and the distribution of knowledge gained from research. Thus, Comensus enables the wider community to access the university and engage in scholarly activity, and provides support for people to engage in the process.

Impact achieved?

Impact has been achieved at several levels.

Impact includes the positive change we see in our members. Members report that they feel more confident, more self assured and gain new skills that they can use in other aspects of their lives:

> *'It gives me a sense of fulfillment, I feel like I am doing something positive in my life.'*
> Service user 1

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[8] https://ec.europa.eu/programmes/horizon2020/en/h2020-section/science-and-society

Members also talk about the positive impact it has on their health and well being and that being regarded with respect makes them feel they can achieve things they have not tried before:

> *' Coming to Comensus has helped my mental health, I don't know where I would be without it'*
> Service user 2

Comensus also has more formal outcomes and has produced a book focusing on service user and carer involvement – McKeown et al (2010) 'Service User and Carer Involvement in Education for Health and Social Care'. The book makes a rare contribution to the body of work on service user and carer involvement in that it is predominantly written by service users and carers themselves. The book explores dilemmas and the ethical constraints of working with service users and carers, as well as the practicalities of this work, all given from a 'real world view' and including international perspectives.

Comensus is often cited as an example of good practice by various professional bodies within quality assurance settings. These have included being recognised as an example of good practice by the College of Social Work and the Health Care Professionals Council – Social Work PCR and validation event May 2013. Comensus was also acknowledged as an example of good practice by the Nursing and Midwifery Council - School of Nursing PCR 2014, and by the General Medical Council Visit Report 2014.

Lessons learned

The successful involvement of service users and carers is resource intensive, but it is not just about money. Beresford (2005) believes that access and support are essential for successful service user involvement. He is concerned with opening up the opportunity to get involved and providing systems of support necessary to sustain involvement. We wholeheartedly agree with Beresford and would go further in that support needs to be sustained; excellent initiatives can be shut down because of a lack of funding. Involvement also needs constantly to reinvigorate itself, it needs to innovate if we are to change institutional culture and keep service users and carers on board and interested in making a positive change.

> *Excellent initiatives can be shut down because of a lack of funding.*

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