INTRODUCTION

The first Educating for Patient and Public Involvement conference explored how the Higher Education community might mobilise teaching, learning and research resources in order to contribute to transforming educational provision to meet the learning needs of patients and service users. We are delighted to have received abstracts from colleagues from universities and the NHS which reflect the great diversity of work in progress to advance patient and service user participation in teaching learning and research. The abstracts are a snapshot of work in progress. Much of this work is inspirational, and what is more, several themes being explored in the abstracts indicate new possibilities for university researchers, teachers and administrators to contribute in helping to create a new learning culture of ‘no decision about me without me’, and in doing so help shape social values in which empowered patients can thrive.

We are immensely grateful to all those who have submitted abstracts and offered posters. Involving patients in research emerges as an important area of activity reflected in abstracts from colleagues working in new ways which often involve patients and service users as co-researchers and evaluators. Work in progress from a diverse range of universities suggests the emergence of a more participatory research practice in which patients and service users become empowered and enabled to fully participate in a wide range of critical inquiry. If we are serious about shaping a new discipline then these examples of the shift towards democratising a wider research culture will be important in defining best practice in patient involvement in research of all kinds.

Co-production is becoming an underpinning concept in new thinking about patient and public involvement in future public service delivery. The abstracts addressing this topic are a timely reminder of how we might use Higher Education resources imaginatively to educate networks of people who are confident and capable to work in new forms of partnership with professionals, so that co-production becomes the way in which patients and service users contribute to future service delivery across health and care. There is much more to be done here. Different approaches to informal and formal learning are described by colleagues working with patients in peer learning, self-management and learning innovation using new technologies.

The abstracts represent a rich resource of ideas, understandings and ways of working which will inform our group discussions on the day as well as the conversations between colleagues and friends that tend to lead to new projects and new opportunities for partnership and mutual learning.
Summary:
EPP CIC provides self-management programmes to improve the lives of individuals and their carers who live with one or more long-term condition. Self-management programmes engage patients to manage their conditions more effectively, thereby reducing health costs. We work with patients, healthcare providers, clinicians, businesses and other partner organisations to embed self-management across all social sectors and address health inequalities. To meet the needs of communities, we work closely with all NHS structures to ensure we can respond to the changes in the health landscape and improve patient outcomes. We also provide training, quality assurance and consultative services for other organisations delivering self-management/self-care programmes. The Expert Patients Programme (EPP), as cited by the NHS UK, (2001, p.22), is a ‘formalised patient education programme aimed at providing the patient with the information and skills necessary to manage their condition within the parameters of the medical regime’. The aim of EPP courses is to develop the confidence to self-care/manage and to motivate the patient to use their own skills. This results in health and social benefits, such as; feeling supported, less isolation, beginning to go out more, more likely to volunteer or take steps towards part time work if condition permits - even return to work, more clued up about how to ask for support and to make things happen e.g. special chair, work times to suit, necessary assistance – the course EMPOWERS individual to take up their place in society whatever it might be.

Service User Mentoring
EPP CIC developed the Service User Mentorship Programme (SUM) as a result of a pilot project working in partnership with South Central Strategic Health Authority. The idea of the programme is to focus on students who are following learning paths that will bring them into contact with people living with long-term health conditions in a professional capacity, and to bring them face-to-face with Service User’s. SUMs are people who have substantial personal experience of living with a long-term condition and are also active self-managers, so have first-hand knowledge of the challenges that living with a long-term health condition brings. All SUMs are volunteers and are enthusiastic in supporting their students’ learning by sharing their knowledge and experience. They have all attended a two-day EPP SUM training event and group mentoring training. Working with SUMs helps students contextualise their learning within areas such as health promotion, engagement and assessment. Students are encouraged to ask their SUMs about their experiences as users of healthcare services, and discuss what support they need from their health professionals.
Title: Educating for Service User and Public Involvement in health and social care research and practice in the North West of England: Resources and Examples of Good Practice

Key themes: Support for Service User & Public Involvement, Health & Social Care Research & Practice

Authors:
Dina Poursanidou, University of Manchester, Marisha Palm, North West People in Research Forum, Mick McKeown, University of Central Lancashire, Karen Machin, University of Central Lancashire, Julie Ridley, University of Central Lancashire
With Karen Newbigging, Laura Able, Kaaren Cruse, Paul Grey, Stephanie de la Haye, Zemikael Habte-Mariam, Doreen Joseph, Michelle Kiansumba and June Sadd (Members of the IMHA research team at the University of Central Lancashire)

Primary Contacts:
Dr Dina Poursanidou, University of Manchester
Email: konstantina.poursanidou@manchester.ac.uk
Dr Marisha Palm, North West People in Research Forum Facilitator
Email: marisha.palm@northwest.nhs.uk

Summary:
Resources and examples of good practice in the development of on-line materials for education, learning and support for service user and public involvement in health and social care research and practice in the North West of England

i) The North West People in Research Forum and Training Working Group (TWG); a regional membership organisation that supports patient and public involvement (PPI) & engagement with health and social care research. A key area of work concerns training, learning and development for PPI; the TWG reviews current training and support resources in the region, identifies gaps in provision and develops signposting and other measures to address these gaps (http://www.northwestpeopleinresearchforum.org/)

ii) A recent study of Independent Mental Health Advocacy (IMHA), carried out by a team of academic and service user researchers in the University of Central Lancashire; the IMHA study constitutes an example of good practice for training and supporting mental health service users to be actively involved in high quality mental health research (http://www.uclan.ac.uk/schools/school_of_health/the_right_to_be_heard.php)

iii) The Community Engagement and Service User Support (COMENSUS) forum in the University of Central Lancashire; Comensus is a valuable resource for supporting the involvement of service users and carers in relevant teaching and research (http://www.uclan.ac.uk/schools/school_of_health/health_comensus.php)

In the context of the resources and examples of good practice mentioned above a number of crucial questions have been raised and reflected upon relating to:

i) Learning points from the experience of educating for PPI;

ii) Successes, challenges and complexities relating to education/training and support for meaningful PPI;

iii) Potential impact and benefits of providing education/training and support for PPI;

iv) Changes required so that the various learning and support models used can achieve meaningful patient and public involvement characterised by genuine co-production
**Title:** From student to peer support worker. A seamless transition?

**Key themes:** Peer Support, Collaborative Curriculum Design & Delivery, Accredited Provision

**Authors:**
Marissa Lambert
Karen Machin, Peer Support Trainer, Freelance

**Primary contact:**
Marissa Lambert, Education and Practice Consultant
Email: marissa.lambert@nottshc.nhs.uk

**Summary:**
The first nationally accredited training for Peer Support Workers in mental health. Organisations and individuals from other arenas, including Higher Education, as well as third sector agencies, may find this development useful when considering authentic involvement and participation of people with lived experience.

Peer Support Workers are people with their own personal experience of distress. These new roles are being introduced across NHS mental health services at a time of austerity, as the emphasis continues towards implementation of recovery and the required organisational changes.

The authors have delivered the experiential peer support training module, to over 200 peers across various NHS organisations including Nottinghamshire NHS Trust, Central and North West London, Hertfordshire Partnership FT and Cardiff and Vale.

The peer support module supports the development of skilled and informed peer support workers seeking work within NHS organisations. The students are people with personal experience of distress, who want to use that experience in their work to support others. Peer support can facilitate recovery by promoting hope and providing support based on common experiences. Peer support workers need to develop a relationship of mutual support with the person they support, as well as the staff they work alongside.

The ethos of the module therefore emphasises working with others as equals, and the facilitator’s role model this style of working throughout.

The 11 day module was co-designed between the Institute of Mental Health (IMH) and independent peer trainers. The IMH is itself a partnership between Nottinghamshire Healthcare NHS Trust and the University of Nottingham. It has pioneered a co-facilitation model that values direct experience, on other courses; including the National Knowledge and Understanding Framework for personality disorder (KUF).

The peer support worker training is co-facilitated by a member of the academic training team from the IMH and an external freelance peer facilitator who emphasises the value of personal experience. Delivery to date has revealed the co-learning that takes place on the training between peers (students), facilitators and members of staff from the host organisation (NHS Trust).

Feedback has included; “What a fantastic course. This has got the most potential to be truly life changing for us” “This is the best thing that’s happened to me in years” and “enjoyable, exhausting, invigorating, and hopeful.”
**Title: Innovative module development; Patient and Public Involvement in Research (PPIR)**

**Key themes:** Collaborative Curriculum Development, Public Engagement, Research

**Author & Primary Contact:** Jane Smiddy: j.e.smiddy@herts.ac.uk

**Summary:**

The Centre for Research in Primary and Community Care (CRIPACC), University of Hertfordshire views patient and public involvement as an integral part of its research practice and educational programmes. An example of this is an innovative module on Patient and Public Involvement in Research (PPIR). This module was established in 2010 as part of the MSc Clinical Research programme, funded by the National Institute for Health Research (NIHR). The Masters programme is offered to nurses, midwives and allied health professionals. However, the PPIR module is also offered as a ‘stand-alone’ accredited module and is open to the public as well as health professionals. The PPIR module was seen as an important and essential part of the Masters programme, with the view that new clinical researchers should be introduced to the idea of public engagement in research. The module was jointly developed by academics within the centre and members of the Public Involvement in Research Group (PIRG). The PIRG consists of service users, carers and members of the public and was established by CRIPACC in 2005. Its work varies but most importantly the group collaborates with researchers to bring a lay perspective and is seen as an equal partner in research and educational initiatives.

---

**Title: The virtual community of Bradton; an online teaching and learning resource**

**Key themes:** Co-production, virtual community, on-line learning

**Authors:**
Michael Hellawell. Strategic lead Service User & Carer Involvement, University of Bradford
Jane Priestley, Academic Development Officer, Higher Education Academy
Judy Steel, Service User & Carer, c/o University of Bradford

**Primary contact:** Michael Hellawell. M.R.Hellawell1@bradford.ac.uk

**Summary:**

The virtual community of ‘Bradton’ has been developed by a team, led by the University of Bradford, with academics, service users, and carers from the COMENSUS project at the University of Central Lancashire, Advocacy in Action in Nottingham, and the West Yorkshire Service Users and Carers Induction Training Group. ‘Bradton’ is an open access web based resource [http://bradton.pbworks.com/](http://bradton.pbworks.com/) that is ‘populated’ by people who have accessed health and social care services. Experiences are presented as online learning materials with all materials being produced in partnership with the service users. These re-useable materials include the use of film and audio, with either the service users representing themselves or being depicted by simulated patients. Bradton is seen to provide a “safe” environment, for service users and carers to share their experiences. The development of ‘Bradton’ has been undertaken as an action research project involving advocates, service users, carers, students and academics.
Title: Service users and Older People’s Mental Health Services: From Engagement to Active Participation: Working with Transitions

Key themes: Service user led movement

Authors:
Nuala Conlan, Involvement and Participation Lead, Mental Health Older Adults and Dementia CAG, South London Maudsley NHS Foundation Trust
Neil Robertson, Associate Director for Education and Learning, Mental Health Older Adults and Dementia CAG, South London and Maudsley NHS Foundation Trust
Stephanie Daley, Lead Occupational Therapist and Recovery Lead, Mental Health Older Adults and Dementia CAG, South London and Maudsley NHS Foundation Trust

Summary:
Over the last three years, we have sought to explore what the recovery, involvement and research agendas mean in practice to service users and carers within older people’s mental health services.

We are seeking to move from viewing service users and their carers as passive recipients of our services to equal partners through our direct engagement processes with service users and carers and also through our working within our organisation to build systems that can harness this agenda.

We are using a community development approach to build community within our service. We want to engender a sense of ownership of the service through mechanisms that get our communities together – including fun, food, and engagement with celebratory events for World Mental Health Day, Black History Month, and other ways of sharing stories. We have used weekly gardening groups and coffee mornings, where staff and service users meet to discuss and support mutual understandings of mental health and recovery as it relates to older people. We are establishing advisory groups comprised of service users, carers, and local agencies, to build more trust with all our stakeholders, as relationships need to be nurtured, sustained and meaningful as time passes. We have delivered extensive recovery training to over 400 of our staff, co-facilitated by staff and service user trainers, and have embedded embedding inclusion and engagement as an integral part of the work tasks of our nurse and occupational therapy clinical specialists, thus seeking to work towards sustainability in future service delivery.

Emerging Themes:
From our service development work, and related qualitative and quantitative research activities we have learnt that inclusion, recovery and research are meaningful concepts for service users and carers of older people’s mental health services. However we have learnt that there are quite distinct challenges in older adults that do not present in working age adults, including Time, as many activists want to see change fast as they feel they want to see change within their lifetime, however this needs to be balanced against the need for sufficient time for engagement, training and development activities. The wider financial climate has meant that resources (both budgetary and time) has challenged our ability to take forward the engagement agenda as fully as we would wish. Other issues for older people include social isolation, physical frailty, transport, and organisational barriers, such as CRB clearance and occupational health requirements. Age discrimination and staff attitudes to positive risk-taking, which we consider to be the greatest challenge facing the involvement agenda for older people.
### Building Research Partnerships: Developing a collaborative approach to support patient and public involvement (PPI) through learning and development.

**Key themes:** Research partnerships, shared learning & development, learning resources

**Acknowledgements:**
Karen Inns, PPI Lead, NCRN, Jack Nunn, Learning and Development Coordinator, Macmillan Cancer Support, Suma Surendranath, Learning and Development Manager Macmillan Cancer Support, Neil Formstone, Macmillan Trainer, Derek Stewart PPI Facilitator and Macmillan Trainer and Gillian Fletcher, Macmillan Trainer.

**Primary contacts:**
k.inns@ncrn.org.uk
JNunn@macmillan.org.uk

**Summary:** Building on their existing partnership, Macmillan Cancer Support and the NIHR Cancer Research Network (NCRN) have developed a range of PPI learning resources. These include *Building Research Partnerships*; a one day workshop designed for mixed audiences of researchers and lay people. [www.macmillan.org.uk/researchlearning](http://www.macmillan.org.uk/researchlearning)

10 one day workshops were run as part of a pilot between November 2011 and August 2012 with over 130 people attending. Evaluations cited impact on practice as well as the opportunity for shared learning and relationship building as key strengths of the workshop. Pilots were delivered through regional PPI forums: providing a platform and framework for delivery. The approach could be adapted for piloting other PPI activities as part of the NIHR PPI Programme and wider partnership initiatives.

### Making Every Conversation Count: The Role of Informal Coaching and Mentoring (A Service User, Staff and Coach Perspective)

**Key themes:** coaching, mentoring,

**Author and primary contact:**
Rachel Hawley, Change Comes From Within Consulting. Affiliation: Sheffield Business School, Sheffield Hallam University.

**Email:** rachelhawley@changecomesfromwithin.co.uk

This paper presents an evaluation of the value of coaching and mentoring with a particular reference to the role of informal coaching and mentoring for staff and patients in the NHS.

The study begins from the premise that coaching and mentoring conversations can open up unrecognized opportunities for people to engage in health care practice and learning. Findings show organisations that want to embed a coaching and mentoring culture, perhaps need to create more of the less used systemic approach, which requires a reflexive rationality of a kind that suspends assumptions from a number of perspectives.

The emerging concept of ‘Making Every Conversation Count’ carries with it implications for educating for patient and public involvement as well as the broader context for healthcare practice and learning. Embracing the notion of an ‘anytime, anywhere, any place kind of learning’ opens up opportunities for all staff, learner, patient and public engagement.

The implications from this work is intended to shed light on future educating for patient and public involvement for coaching and mentoring practitioners, health care leaders and educators - to develop and share new insights based on valuing lived experience.
**Title: Service user involvement in educational and research activities, Faculty of Health and Social Care, London South Bank University**

**Key themes: Service user involvement in education & research**

**Author & primary contact:**
Margaret Harper, Chair of Service User Involvement Steering Group, Faculty of Health and Social Care, London South Bank University  
Email: harpermm@lsbu.ac.uk

**Summary:**
A Service User Involvement Steering Group with staff members from all departments/research and service users was set up 5 years ago to promote and facilitate the development of user involvement in the Faculty activities. To enable this further, they produced ‘Guidance for involving service users and carers’. The Faculty has been working with service users in a number of educational and research activities. Various activities in partnership with service users have taken place, such as the production of educational DVDs on dementia, older age and social care issues. Departments such as Mental Health and Social Work have been collaborating with service users in activities ranging from teaching planning and delivery, and student recruitment and selection. Research projects taking place showcase collaborative and user-led projects, where service users trained in research, conducted interviews, analysis and writing up.

---

**Title: Service user involvement in research and post graduate teaching, Faculty of Health and Social Care, London South Bank University**

**Key themes: Service user engagement in research, service users as peer researchers**

**Author and primary contact:**
Markella Boudioni, Senior Research Fellow, Institute of Leadership and Service Improvement, Faculty of Health and Social Care, London South Bank University  
Email: boudiom@lsbu.ac.uk

**Summary:**
A subtheme of research at the Faculty is entitled ‘Service User Engagement and Experience in Research’. A group of academics, researchers and service users work together. It is led by Markella Boudioni and has the dual aim:
1. To promote and facilitate research with service users, patient and public
2. To promote and facilitate research about service user, patient and public engagement and experience.

Service Users collaborate in brainstorming sessions, group meetings and research planning and design. Some have also worked in collaborative and user-led projects, conducting interviews and qualitative analysis.

Training in qualitative methods is also delivered to service users to equip them with research skills and support them in conducting research themselves.

Service users are also involved in planning and delivering sessions about PPI/PPE at the MSc Leadership and Service Improvement in Health Care and the taught sessions of the Professional Doctorate for Nurses and Allied Health Professionals.
Title: Patient Empowerment in England and Greece: Cross-national Settings, Organisational Systems and Professional Cultures

Key themes: International patient empowerment

Author and primary contact:
Markella Boudioni, Senior Research Fellow, Institute of Leadership and Service Improvement, Faculty of Health and Social Care, London South Bank University
Email: boudiom@lsbu.ac.uk

Summary:
This is an international comparative study on patient empowerment policies and their application in England and Greece. The national settings of patient empowerment, patient involvement or patients’ rights, are explored in the two countries. Their application, i.e. the organisational systems, structures and mechanisms in 6 cases – public hospitals in the two countries, as well as these are perceived by key stakeholders, challenges and facilitators are also examined. Re-organisation of health care systems, particular the public hospitals, which may enable greater access to information and knowledge, create new dynamics and redefine the role of patients and enable a more effective partnership with health and other professionals, is recommended. Although the research was based on two European countries, some recommendations may have international appeal.

Title: Conceptualising and Using Learning from Patient and Professional Experiences: Implications for Developing PPI in Medical Education, Research and Evaluation

Key themes: Community development practice, shared learning

Author and primary contact:
Hament Patel - Expert Patient Teacher Trainee at the London Deanery
www.londondeanery.ac.uk and Director of OCP Ltd www.ocp-ltd.com

Summary:
The paper draws on the author’s wide background in health and social care research and development work with both patients as service users and in communities. The paper also reflects on the authors experience as an adult education lecturer who has worked with students on a health studies programme piloting a different approach to teaching and learning about PPI in health services research. The paper will start by setting out and explaining what are the powerful ideas and models from adult learning and community development practice that can inform and help change patient participation in medical education, research and evaluation. The presentation will then go onto discuss current challenges around this for different learners, i.e., professionals, patients and commissioners. The opportunities for improving PPI and community-based engagement afforded by notions around co-production, emancipation and ownership will also be explored by considering in relation to different case examples from both the authors own experiences and beyond. This paper will dovetail to that given by Delia Muir about creative practices to support PPI work. This abstract is informing thinking about a project with the London Deanery which aims to explore and pilot innovative approaches to improving shared learning and working between health professionals, patients as service users and communities. The project will draw on the rich working knowledge and skills of the author, experiences of project participants and also different major contributions from Delia Muir, and staff from a charity organisation called Involve http://www.involve.org.uk/
| Title: Performing Co-production: An innovative model for creating dialogue |
| Key themes: Co-production, simulation performance, real life narrative |
| Authors & primary contacts: |
| Delia Muir - Expert Patient Teacher, London Deanery & Patient and Public Involvement Officer, Leeds Clinical Trials Research Unit [www.pursun.org.uk](http://www.pursun.org.uk)  |
| Penny Morris - Education Lead, Professional Support Unit, London Deanery [www.londondeanery.ac.uk](http://www.londondeanery.ac.uk)  |

**Summary:**
Co-production is a vital concept in today's rapidly changing healthcare environment. One of the key challenges when trying to achieve co-production is creating meaningful dialogue between people who bring very different expertise and experiences. This can be particularly challenging when service users are asked to become part of systems and processes which are new to them, but familiar to the professionals involved, for example, research or service design. How can we make these processes engaging and accessible so that everyone can contribute?

We have been working with applied theatre and performance practices to help redefine people’s roles and keep the service user voice strong in a variety of health contexts. In particular we have worked with a long standing simulation performance model. During this presentation we will present two examples of this innovative method, as well as considering the origins of the work and wider implications for PPI education.

**Case study 1 – The Community Dialogue Project**
The Community Dialogue Project was commissioned to pilot co-production approaches to the design and delivery of services. As part of this we facilitated a dialogue event with health professionals from one Leicester general practice and local community members, using our simulation performance model. The ‘character’ for this simulation was developed with local patients, many of whom attended the event.

**Case study 2 – The Severe Pressure Ulcer Project**
The Severe Pressure Ulcer Project is a qualitative study looking at why patients develop server pressure ulcers. The project team were keen to explore if service users with personal experience of pressure ulcers interpreted the data in the same way as a largely clinical research team. Simulation and videos were used to present the project data to service users, researchers and clinicians as a live case study.

We will also look forward to a new project currently being developed by the London Deanery, which will build on this work. This project is explored further in an abstract by Hament Patel.

We have found that powerful real-life narratives, balanced by the safety which simulation provides, can create a common focus for all. This can lead to the mutual empathy needed for co-production.
Title: What is the lived experience of patients, who have self-harmed, of contact with mental health services in a general hospital environment?

Key themes: Service user consultation. Research

Author & primary contact: Sandra Walker.
Senior Teaching Fellow, Mental Health Team, Faculty of Health Sciences, University of Southampton
Scwly10@soton.ac.uk

Summary:
Service User involvement is increasingly being recognised as being central to health and social care policy and practice, including research (Lieba, 2010). Wallcraft (1998) points out that historically, mental health research has mainly ignored the views of the recipients of care and that the patient's subjective experience is often transformed into some kind of quantitative measure of observed behaviour. Leiba (2010) states that it is essential to involve the service user as early as possible in the design and planning of research as they can have a real impact on the direction of the research and ensure that it remains valid from a service user perspective. In view of this and as part of the research design of the above mentioned research project, a service user consultation was carried out. The service users were comprised of current and ex patients who had all had experience of self-harm and had had a psychosocial assessment. The reason for the consultation was to do the following:

- Explore whether the research question is valid and worth asking
- Ascertain what questions they felt were important to ask those who take part in the research
- Ascertain what outcomes they would like to see from the research
- Gather volunteers to be part of a steering group to advise the project
- Recruit volunteers to help with writing articles at the completion of the research for publication

Editorial Acknowledgements:
Jane Priestley, Higher Education Academy
Ed Rosen, London South Bank University
Jessie Cunnett, Patient and Public Involvement Solutions

All Rights Reserved – September 2012