Editorial

Welcome to the spring edition of INVOLVED! The language of public involvement continues to evolve and the first piece in this edition is about how we are changing our language at UWE to be more inclusive. This reflects the growing numbers of programmes; now more than 15 individual programmes in HAS that have members of the public involved. This involvement includes programme design, validation, teaching, learning and assessment activities and ongoing monitoring and quality. It also mirrors the language of public involvement used in research, another area where UWE is developing a good reputation.

We are currently re-vamping the Public Involvement in Professional Education web pages and these will be placed on the MyHAS intranet. There will be links to positive ways of achieving public involvement, including algorithms and best practice documents. Also publications and free resources developed with members of the public which you can either, access in the library, or electronically and embed in your blackboard resources.

In this edition you will find examples of innovative work taking place in our educational programmes here at UWE. There is an interesting article about listening to people’s experience of health care and what they think the essential skills, attitudes and knowledge of community health staff are. This underpinned our successful tender and will ensure the new Community Award has a real world foundation based on peoples lived experience. There are also short articles about hosting a conference with the involvement of children and young people, public involvement in student adult nurses’ theory assessments. There are also teaching and learning activities undertaken across the Faculty involving co-teaching between academics from the Learning Disabilities academic team and people with learning disabilities and family carers.

We are always eager to hear of new public involvement initiatives so please share them. We are sharing the excellent achievement of Jackie Edwards, winner of a new researcher award.

I hope you enjoy this edition

Kim Scarborough, Guest Editorial

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If you would like to receive involved! in a different format (eg large print, tape, Braille) please contact Fiona Earlam, Service User and Carer Administrator, e-mail Fiona.Earlam@uwe.ac.uk, telephone 0117 32 88556

The submission deadline for the next issue of involved! is 4 May 2015. To submit articles or for more information, e-mail Public.InvolveHAS@uwe.ac.uk
The involvement of people with learning disabilities and family carers in a range of activities

People with learning disabilities are among the more excluded and vulnerable people in our society and many reports indicate that they receive a poor service from the NHS. In the new Confidential Inquiry in the premature depths of people with learning disabilities (Heslop et al. 2014) undertaken by the Norah Fry centre in Bristol you can read of the 1200 premature deaths. At UWE we want to prepare all health care professionals to challenge this institutional discrimination and give people with learning disabilities excellent care. Poor care is not only about wider management issues, it is about the interactions each individual member of staff has with their patient. Our UWE students can already make a positive difference in people’s lives. To work towards this aim people with learning disabilities and family carers are working with the Learning Disabilities nursing academic team to embed teaching across the three year curriculum and are running sessions about learning disabilities across nursing and midwifery, allied health professional and healthcare science programmes.

If you want to know more, or would like this type of inclusive co-teaching in your programme contact Kim.Scarborough@uwe.ac.uk for a chat, students love the sessions and so do we.

Healthcare science activity

A plan for ‘public’ involvement in Healthcare Sciences in the Department of Biological, Biomedical and Analytical Science is underway following the appointment of a working group of staff and patients. The group comprises programme leads for Healthcare Science ‘Physiological Sciences’ (Kathryn Yuill), and ‘Life Science’ (David Qualtrough). Along with Viv Rolfe, the team are exploring how to best embed public involvement into the governance and delivery of these programmes.

Teaching activities include the use of public volunteers to voice the patient simulators at Glenside, and James Willis who is a cardiac physiologist and member of the team, is running hugely successful sessions and coordinating discussions between students and patients regarding their experiences. James’s work was highly commended in the recent Modernising Scientific Careers re-accreditation of Physiological Sciences. For ‘Life Sciences’ which is the training pathway for NHS Biomedical Scientists, some of the initial work is at a more fundamental level, exploring with patients, students and staff the relevance of the public voice in what ostensibly is a laboratory-based discipline. It is clear from these early discussions that this involvement is hugely important, and from an R&D perspective increasingly relevant with the growth of point-of-care testing and community medicine.

It is anticipated that public participation will have a significant impact not just in enriching the educational opportunities for students, but also feed into the work of the research teams within the department. The Healthcare Science team are also developing a programme of research around their work and have a case study currently in press. This is an entirely new field of study for these subject disciplines.

Viv Rolfe, Associate Head of BBAS

People in Health West of England – Progress and Practice in Public Involvement

A date for your diary! Regional public involvement event - Wednesday 3rd June 2015

Come along for:

- A national update from Simon Denegri from the National Institute for Health Research (Chair of INVOLVE and National Director for Public Participation and Engagement in Research).
- A progress report on the work of the regional public involvement group - People in Health West of England
- Examples of good involvement practice from the region
- Opportunities to develop your involvement network.

More information will be on our website soon http://www.weahsn.net/prwe/ and from Kim Thomas, Kim.Thomas@weahsn.net
Building Understandings:
Child, Youth, Family 
and Disability

10 - 11 June 2014
Glenside Campus, UWE

Katherine Runswick-Cole, Senior 
Research Fellow, Manchester 
Metropolitan University, invited us to 
host the 7th Child, Youth, Family and 
Disability Conference at UWE and we 
were delighted that 63 people attended 
coming from Newcastle to Cornwall.
Participants enjoyed the “vibrant, 
friendly, supportive environment” thanks 
to the work of the CUSP team, finance, 
Glenside reception, porters, catering, 
IT support and social work student 
volunteer!

Eighteen presentations were made by young 
disabled people, parents of disabled children 
and disabled adults, researchers with lived 
experience and professionals, academics and 
students in social work, education, health, 
mental health, physiotherapy, and music 
therapy. We heard how families focus on 
enjoyment of life and learnt how disabled 
children participate being an advocate, 
mentor, advising on service information 
and staff recruitment and being involved 
in research. Projects included employment 
in the NHS and Manchester Metropolitan 
University, peer support in mental health 
and disabled children’s access to cycling and 
recreation spaces. We understood more 
about experiences of discrimination that 
included complicity with bullying, trauma 
from ‘being done to’, escalated crisis putting 
all family members at risk, the considerable 
demands made of families and at the same 
time low expectations held of their children.

How can people decide on their own 
‘mountains to climb’ and how can we build 
understanding communities in a culture of 
‘blame’ and a preoccupation with diagnosis? 
‘Don’t make us feel bad’, a young person 
said. When professionals were listening, and 
were honest and confident to give change a 
go, it made all the difference.

For more information contact 
Tillie.curran@uwe.ac.uk or 
K.runswick-cole@mmu.ac.uk

MA Success and New Researcher 
award for Jackie

Jackie Edwards is a member of the 
BSc(Hons) Learning Disabilities Nursing 
programme team. She became involved 
in the programme as a family carer 
teaching our LD nursing students about 
carers’ experiences and legislation, in 
particular Valuing People.

Jackie has worked with the Valuing People 
team in the south west, and has recently 
undertaken an MA in Dance Movement 
Psychotherapy. She ran a workshop on dance movement psychotherapy at 
our South West Learning Disabilities Nursing Conference at Glenside this year 
which evaluated very well.
The Journal Body, Movement and Dance in Psychotherapy have accepted for 
publication Jackie’s article from her MA project. This has resulted in her being 
awarded New Researcher 2014 by the Journal editorial team.

We would all like to congratulate Jackie, and I know our learning disabilities 
nursing students are eager for more dance movement psychotherapy 
workshops.

Kim Scarborough 
Faculty Lead in Public Involvement 
Senior Learning Disability Nursing Lecturer

The terminology of involving people in 
educating health and social care professionals

The Faculty of HAS previously used the term Service User and Carer to 
describe the end point consumers of health and social care services, and/ 
or their unpaid, often family, carers. Whilst accepting that some people 
are attached to the term Service User and Carer, other people involved in 
the Faculty view the term User as pejorative and feel service user does not 
represent them.

We have debated more suitable terms and acknowledge that an overall 
consensus has been difficult to achieve and we do not want to label people. 
The term Public is a generic term preferred by many of the individuals who 
support student learning at UWE because it is inclusive. It also reflects how 
research has Public Involvement and the government drive for members of 
the Public to be fully involved in decision making. When using the term 
Public within the Faculty we mean people who may see themselves as 
patients, service users, survivors, carers, parents, clients, pregnant women, 
children, lay members, people with lived experience, including people who 
experience long term health conditions, acute healthcare needs, disabled 
people, people with learning disabilities and experts by experience. We hope 
the term Public will encourage more people to become involved in helping 
UWE students learn and develop.

In order to specify that we are referring to people who access the health and 
social care services that UWE students are being trained to deliver, we are 
now using the term Public Involvement in Professional Education (PIPE). This 
will distinguish our work from other work streams that use and understand 
the term public involvement differently to us, such as involvement in research 
or knowledge exchange activities where academics go into the community 
to provide learning activities. So you will see email addresses, peoples’ titles 
and room names change to reflect that we are now using the term Public 
Involvement in Professional Education.
In the year two adult nursing module “Planning and Delivering Nursing Care” we have created a unique opportunity for students to work with service users and carers in developing their assignment project. We hope that by involving service users and carers in the planning stage, students will gain valuable insight into what is relevant and important to the people who would benefit from the resource. We also hope that this will give them a deeper understanding of the process of supporting adults who are managing a long term condition in real life practice, which is a major theme of our module.

In this project module assessment, students are required to develop and critique a health resource for a specific group of service users and carers. This is based on a range of case studies and pathways that are embedded in our curriculum and the focus is on supporting self-management of long term conditions. This health resource will cover a range of aspects of care that a service user or carer may wish to access at various points in their life. Students are asked to create a unique resource that:

- Takes into consideration a range of service user and carer needs.
- Recognises and draws on existing resources such as websites, videos, leaflets, blogs, ensuring that these are evidence based and reflect service user and carer perspectives.
- Presents this in a user friendly way and uses a range formats (websites, leaflets, videos etc.) from evidence based sources.

Students then write a supporting paper that evaluates how effective their resource might be. They are asked to critique the resource they have created and the sources they have included to show awareness of strengths and limitations of different sources and formats, including service user and carer views of this.

Service users and carers with experience of managing a long term condition will be invited to participate in small group sessions where students will be planning their health resource. Facilitated by the academic team, students will have the opportunity to share the work they have done so far and the ideas they are developing with service users and carers.

Supported by the facilitator, the service users and carers will have the opportunity to give feedback on the student plans and ideas and make suggestions on content and format of resources as well as sharing good ideas from their experience or aspects that they could improve on which students may not have considered.

Students will then be able to incorporate the service user and carer perspectives within their resource and will be able to draw on these examples within their supporting paper to illustrate strengths and limitations of their resource.

We are going to evaluate the student experience of this approach and hope to build on this in the future. This was inspired and adapted from an assessment that has been successfully embedded in the Learning Disability (LD) Nursing programme and we are grateful to the LD team and the Fiona Earlam (Public Involvement Administrator) who have shared their knowledge and experience with us.

What do our Mental Health Nursing Students think about sessions with service users and family carers?

“It gives a much valued context to the things we are learning as well as inflaming further, a passion to get things right for service users and their families.

Why do nurses change once they qualify? We will now have yesterday’s session to remind us and help keep the fire burning bright when faced with post qualification workplace issues that can lead to apathy and distraction from our core purpose - the ‘centreing’ of care around the person and their needs.

Thanks to all involved for daring to inject this exciting kinaesthetic interactivity into our learning programme.”

Mental Health Nursing student

“I would like to use this opportunity to let you guys know that this is by far mile the best learning experience I have ever had. I can confidently say to you guys now that that experience has put more fuel into my engine and I will continue to strive hard to make the difference this country and the world needs in nursing care.

Please keep up with the hard work and stay blessed.”

Mental Health Nursing student

“It gives me a sense of belonging just by the virtue of coming into a welcoming environment and that I share in confidence and it also gives me a feeling of fulfilment to know that what I invest today, be it my time or sharing experiences will stand all future nurses in good stead for quality practice and care.

And in my bid to help people I’m actually or would like to think and believe that my experiences will somewhat guarantee and improve the care received by every mental health patient or help set precedents in the level care.”

Service User involved in Mental Health Nursing Programme