

# Human and Health Sciences Public Partnership Group: Empowering People to Influence Change



Issue 2: December 2014



## Welcome from Professor John Playle, Dean of the School of Human and Health Sciences

"The Public Partnership Group was formed in 2013 and consists of a committed team of service users, carers and staff within the School, who had been working on the strategic development of service user and carer engagement within the University for a number of years.

"In this newsletter I am delighted to see how much has been achieved by the Group. The plans to pilot the delivery of training sessions for service users and carers have now come to fruition and were highly successful. The evaluation of these sessions has led to development of high quality support materials and a better understanding of how to design and deliver such sessions in the future.

"National panels including the Health and Care Professions Council (HCPC), who review

Social Work courses and the Nursing and Midwifery Council (NMC) who validated four new Master's courses in Nursing, both praised the excellent work of the Group and the genuine commitment to engagement they experienced.

"This coming year will see the Group working on consolidating their role, in particular developing a more embedded support structure and hosting the National Learning by Experience Network (LEN) meeting.

We continue to be highly committed to engaging service users and carers throughout all our work as experts by experience and the essential contribution that they make to ensuring we are able to develop and deliver high quality courses. I look forward to seeing the work of the Group continuing to grow in the coming year."

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### Upcoming events

#### Thank you certificate

Frank Adams, one of the Service Users, who leads on the Public Partnership Group, suggested that a 'thank you' certificate could be awarded annually to members of staff who provide outstanding support to disabled people

accessing the University campus. If you would like to make a nomination please contact Janet Hargreaves by 1 December on email. [j.hargreaves@hud.ac.uk](mailto:j.hargreaves@hud.ac.uk) or tel. **01484 471822**.

## The Lived Experience Network

The Lived Experience Network (LEN) is part of the Higher Education Academy (HEA) Health and Social Care Cluster. This consists of a network of people with a shared interest in patient and public involvement in higher education.

The aim of the Network is to develop a critical alliance of people with real life experiences, students and academics, in order to enhance and improve practitioner education, patient experience and associated research in health and social care.

This is led by Jools Symons, Public and Patient Involvement Manager at Leeds Institute for Medical Education supported by Jane Priestley, Academic Lead from the HEA for Health and Social Care. The membership of the network

has increased nationally and a number of showcases have been held over the last two years in Leeds, Southampton, Surrey, Liverpool, Bradford and Sheffield.

Christine Rhodes, Head of Pre-Registration at the University is linked to the network and a showcase will be held at the University on 11 August 2015.

## International Day of Disabled People

To celebrate International Day of Disabled People on 3 December, the Public Partnership Group will have a stall on 3 December in Student Central between 10.00am and 12.00pm. Please come along for chocolate and chat if you would like to join us and find out more about the Group.

## Reflecting on the year

### Key professional bodies visit the Social Work Department

May 2014 was an exciting time for the Social Work Department as it was visited by representatives from the Health and Care Professions Council (HCPC) and The College of Social Work (TCSW). This was the culmination of months of preparation and gathering of evidence, in order to illustrate to these professional bodies the overall quality of the student experience on the Social Work BSc(Hons) and MSc course.

The Social Work Department were keen to demonstrate how they involved service users and carers in the planning, delivery, assessment, monitoring and review of the programme, which was clearly evident in the paperwork. The reviewers also spoke at

length to a group of service users and carers about their experience, who were very positive about working with the Social Work team. They felt valued, respected and safe. One also commented, they loved to see how the students developed and progressed, with particular reference to the skills days they had helped to design, deliver and assess.

The outcome for the department was very successful and they would like to thank the service users and carers, who not only offer a valuable partnership to staff and students but who also undoubtedly helped the professional bodies to make such positive comments about the courses.

Judith Oliver, Senior Lecturer in Social Work

## Piloting service user and carer skills development sessions

One of the initiatives the Group wanted to achieve was to design, develop and evaluate training sessions for service users and carers. They were frequently asked what help and guidance was available for service users who were speaking to students, attending meetings or involved with student applications.

The Group wanted the service users and carers to feel confident to volunteer for involvement in the design and delivery of research, so decided to pilot three skills development sessions. The two hour sessions focused on teaching, involvement in meetings and applicant interviews, and research. Evaluation was built into each session, for which ethical approval was gained from the School.

The first session was piloted with ten service users who volunteered to attend. This was designed and delivered by three of the service users from the Group, who were supported by four other members that acted as participant observers. The session was successful with

the content and high quality materials produced praised. However the Group also realised they need to learn more about managing a very mixed group of volunteers to ensure they recognise and respect the amount of expertise in the Group, whilst making people who are new to the University feel welcome and safe.

The second session, which was designed and delivered by one service user and one academic colleague, was attended by eight volunteers. This was organised around informal groups where at least one member of the Group hosted each table to ensure everyone was involved and had support. The content and quality of the session was again praised and the change in pace and structure improved the experience for all. The Group finished the second session feeling more confident that they had a working model, which they are keen to develop further as they prepare to hold the third session on research, which has been postponed until Easter 2015.

## Regional Higher Education Institutions (HEI) Service User and Carer Group Meeting

Elaine Powell, one of the Service Users involved with the Group, attended the first Regional HEI Service User and Carer Group Meeting hosted by the Social Work Department at the University of Hull. Elaine was accompanied by Health and Community Development student, Rebecca Ross and Senior Lecturer, Kate Wood from the University's social work team. This was attended by 28 representatives from nine universities around the region.

The meeting featured a talk by guest speaker June Sadd from the Social Care Institute for Excellence, who gave a biography of her contribution to involvement and a 'ten minute challenge' where each university was invited to share information about what their university is doing and the challenges they face. This enabled the attendees to transfer knowledge, share best practice, find common ground, as well as forge links and partnerships.

## Goodbye and thank you

Dr Chris Davies retired from the University last year after a long and successful career in podiatry. As the lead for the Podiatry Clinic, Chris played a particularly important role in championing a service user group for the Podiatry Clinic making their involvement in clinic developments and student education a daily reality.



Dr Phil Fletcher-Cook and Kath Padgett [pictured above] who also recently retired will be greatly missed. From physiotherapy and mental health nursing respectively they actively supported service user involvement. Kath led the service user strategy for the health courses in its early years, forming a starting point for the current group to develop.

## Congratulations to Michelle Williams

Congratulations to Michelle Williams (pictured right) who was awarded her Health and Community Studies BSc(Hons) in July 2014. Michelle joined the Group as a student placement two years ago, and has remained an active volunteer since.



## Congratulations to Christine Rhodes

Over the past five years many of the service user group have been following, and in many cases collaborating with Christine Rhode's Phd, which investigates the agency of service user and care involvement in health and social care education. Christine was awarded her PHD at a graduation ceremony on 11 November 2015 [pictured below], which many members of the Group attended to support her.



## Service user experience

### Spotlight: An autobiographical note' on a service user's life

"Let me make one thing clear, I never meant to be a doctor. I was very good at mathematics and science at school and always wanted a career in science or engineering. My father was a distinguished computer engineer but was disillusioned about his career and fascinated by the human brain which, despite operating thousands (now millions) of times more slowly, could do so much more. He encouraged me to consider a career in biological research.

"At the school careers service I was encouraged to apply for a medical degree. I was not keen on this but was won over when I was told that I could take up research as soon as I qualified. I studied physiology at Cambridge and was again advised to study a medical degree and then apply for a research job.

"I started with depression as a medical student but with help from medication, I qualified and joined the Royal Air Force as a Medical Officer, hoping to work in Aviation Medicine, the subject taught by my professor at Cambridge. While I was serving, my periods of depression started to be interspersed by bouts of over-excitement.

"After a particularly violent attack, I was sent to hospital and diagnosed with bipolar affective disorder and started on lithium prophylaxis. At this point, it emerged that I had a strong family history. My mother had taken an overdose a few years before, taking my father's anti-depressants, and her grandfather and uncle had both committed suicide. As was common in that age group, silence had been observed about these events.

"The pattern of illness I suffered was called 'rapid cycling'. I would become very depressed and incapable of working effectively. Slowly, this would get better over a period of weeks or months then something would

get me over-excited and aggressive if opposed. This 'high' would last for a short period, perhaps only 48 hours or so, and be followed by deep depression. Although these manic episodes were called 'highs', I always found them most unpleasant. They also put a great strain on my marriage, while the depressed periods harmed my career.

"My first wife, Marian, suffered very badly from my manic attacks and always complained that no one would believe how bad I was, as I was usually back to normal by the time I could be seen by a doctor.

"My experiences in the RAF and at medical school confirmed my view that I was not cut out to be a doctor, lacking the stamina, retentive memory and certain inter-personal skills required to be a good clinician. On the other hand, I received enthusiastic encouragement to pursue an academic career in civilian life. I was described as 'intellectually gifted and a good communicator' and assured by the former Dean of my medical school that I would easily obtain a lectureship.

"I was short-listed for a lectureship at Oxford and offered a research fellowship at Cambridge subject to obtaining a Medical Research Council (MRC) grant. The MRC were unwilling to pay for the training of a medically qualified physiologist and the University were equally unwilling to pay my salary themselves so instead I obtained a place on a training scheme in public health. The repeated possibilities of career success would set off my condition and make me 'high' only to become very depressed when they fell through.

"From 1983 to 1985, I had a happy time in public health, learning about statistics, epidemiology and health economics. I passed the part one examination for the Membership of the Faculty

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of Public Health Medicine in 1985. At that, my general practitioner stopped the lithium as all seemed well but then my father died and I started to become depressed again. It was clearly unwise to stop my medication without consulting a psychiatrist.

“My contract came to an end in 1989 but history repeated itself and I was unable to obtain a research post or to stay on in Shropshire. I obtained a consultant post in Yorkshire but was unable to cope with the highly political nature of the post and took early retirement in 1993.

“Three years later, I was passed as fit for work again. I had not been idle during that period but gained a degree in electronic engineering for the University of Leeds. With qualifications in public health and engineering, I felt confident of finding work in one of the fields or possibly in medical engineering but 16 years later I am still out of work.

“A good deal is said of stigma and discrimination against people with mental health issues but I was never turned down because of my illness. Discrimination about my age and gap in my work record were all that was required. Marian experienced similar difficulties in returning to teaching after a long gap raising our family.

“There seems to me to be little point in specific action to help people like me with mental health problems to get back to work after illness until this country returns to full employment. Until then, there will always be someone else as well qualified but with more recent experience.

However, it is clearly unacceptable that someone like me with three university degrees and the same number of postgraduate qualifications should be among the long-term unemployed despite improved health.

“A few years ago, my psychiatrist became worried about my renal function. (Kidney damage is a complication of long-term lithium therapy). My medication was changed to one of the newer mood-stabilising drugs, Olanzapine, and the results were striking.

“My alternations of mood were greatly reduced and judged to be well within normal limits, so this year I was discharged from psychiatry outpatients. I only wish this therapy had been available when I started with this illness 35 years ago. It would probably have saved my marriage and my career.

“Much is said of ‘talking therapies’ but I have found them unhelpful and distressing. Mine is clearly an inherited biochemical problem and one best dealt with by medication.

“Since retirement, I have been working as treasurer for the Doctors’ Support Network, a charity supporting doctors with mental health problems, and it is clear that I am not the only doctor to get through higher training then be pensioned off.

“I calculate that the cost of my training and subsequent pension must amount to nearly a million pounds, a wholly unacceptable waste both of talent and of public money. An over-rigid career system is clearly to blame. I could have managed my duties in Shropshire indefinitely had I not been forced to seek promotion, despite poor health. Given adequate treatment and properly funded training in research I could have done very good work.”

## Creating a digital story

The Pilgrim's project led by Pip and Tony enables people to work together to create a digital story about their lives.

For further information visit: [www.pilgrimprojects.co.uk](http://www.pilgrimprojects.co.uk)

"I have always wanted to share my caring story for a long time, so this was an opportunity I wasn't going to miss.

"I wasn't quite sure how I would achieve this. The expert facilitators worked with a few people, to get us bonding initially then the real work started. We shared our personal thoughts, listened to each other, shared ideas and sounded out our stories before we recorded them. Pip and Tony worked with us on a one to one basis drawing out the messages we wanted to share with personal photos, adding music and giving a name to our voices.

"I did worry that I might not be able to condense my life into three minutes and have a digital story with a powerful message. In two days I did just that, and I'm proud of the outcome."

Kausar Iqbal, Service User

## Being Involved in Nurse Training: a poem

I saw nought but sadness in my life  
Then a quiet voice said 'add your measure'  
What did that mean? Interest in my strife?  
'Your experiences are a treasure',  
of problems faced and problems reduced.  
A chance for new beginnings produced  
For others and for self  
we are all part of life's wealth  
So how can you be of use.  
To show others that things can change.  
How you do, has a wide range  
From indifference and abuse  
We start at the beginning.  
The hearts and minds of students winning.  
To light the fuse and let it burn.  
So students' compassion and consideration learn.  
The differences made will explode and change  
your perspective. Your value will be seen,  
So come and be part of this  
This chance you should not miss

Barrie Holt 2014 Service user

## Student experience

### My Involvement in the midwifery selection process

“I was offered the opportunity of visiting the Birth Centre at Huddersfield Royal Infirmary in February, to discuss my passion to train as a Midwife.

“Following this, I was then invited to be involved in the interviewing and selection process for the Midwifery course. During the process, I was an active participant in all aspects of the day and was able to meet and talk with aspiring midwives, observe the group activities and one-to-one interviews and provide feedback on each applicant.

“This experience gave me a great insight into what the Midwifery team are looking for in a potential student midwife and how they facilitate their interviews and group tasks.

“It was an incredibly positive experience from which I gained further knowledge and awareness of Midwifery as a whole; including the course content, prospective placements and the diverse experiences of not only the midwives, but also the applicants.

“Being involved with the selection day strengthened my passion and determination to become a Midwife so much more and enabled me to feel less anxious about the interviewing process. It undoubtedly re-confirmed what I already knew within me, that Midwifery is the career for me and one which I will be pursuing with great happiness and excitement in the future.

Rebecca Ross, a third year student studying Health and Community Development BSc(Hons)



Generic photo from the Midwifery BSc(Hons) course



## Walking in the shoes of a service user

Whilst studying the Social Work BSc(Hons) and MSc courses, the students complete the Working Together module, which asks them, as part of the assessment, to write a poem, story or diary entry from the perspective of a service user they are going to discuss in a case study. Below is an example of one of these very poignant pieces of work.

### Diary entry

I want to get clean!

Why does nobody want to help me with my depression? I will struggle to stop drugs until they give me something for my depression. I feel that I am not being treated equally, if I was not an addict then the support and drugs would be given to me. The doctor just tells me to stop the heroin and I will feel better.

If only it was that simple.

How can I go to rehab next year and feel positive about getting off the drugs when I am feeling this low? I wish people would stop blaming the heroin for everything that happens in my life!

Who even told social services that I have relapsed? I have been told that I can't have contact with my daughter until I am off the drugs. I am determined. I need to be. Kate is the only part of my life I can be proud of.

I have a year until my rehab program starts. After that I can have contact with Kate. I miss her so much. I cannot believe that I am going to miss her 13th birthday. She is becoming a

teenager, time goes so quick. What sort of role model am I to her?

After rehab they want me to relocate to Sheffield after the program. How do they expect me to travel 30 miles to see Kate?

How will I be able to afford it?

I can't get a job. Who would employ me? A low life. A smackhead.

The only thing stopping me from just ending my life is Kate. Sometimes I wish I had cancer or something so my life would end without feeling the guilt.

I don't want my daughter to go down the same path as me. I wish that doctor would give me the pills I need them to stop me feeling like this. He just looks at me in disgust, like I am not worth the help. Does he not understand how difficult it is for me to ask for help knowing what he is going to say?

Life was rubbish again today. I would like to think that tomorrow will be better but I know it will be the same, the same as every day.

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