



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

“Welcome to the first issue of the newsletter from the Human and Health Sciences Public Partnership Group.

“Collaboration with Service Users and carers is a crucial part of the work undertaken in the School, including teaching, quality assurance and research.

“The School has established a number of strong partnerships and I am delighted to see them becoming more formalised, allowing further development.

“I hope that you will find this newsletter useful, as it outlines the current work and future aims of the group.”

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About the Human and Health Sciences Public Partnership Group

The School of Human and Health Sciences believes the involvement of a wide range of people experienced in health and social care is of great value to the education of its students.

Their stories and history of experiences can help students to understand the needs and expectations of the individuals they will be working with. This also enables them to develop the right values, knowledge and attitudes to support their client group, ultimately putting the person at the centre of care.

Through their involvement in education and research, Service Users and carers have the opportunity to make a difference and influence future health and social care.



Academics within the School work alongside Service Users and carers, helping students to apply and relate theory and research to their practice. Learning in the School is a joint endeavour and Service Users and carers, students, academics and practice colleagues work in partnership to achieve the goal of continuous improvement to the delivery of care.

How you can become involved

There are many ways you can be involved where your skills maybe of great value and these include:

- Talking about your own personal experience to students
- Interviewing
- Curriculum development
- Attending meetings and seminars
- Assessments and research

In the coming year we aim to pilot three training sessions focussing on various topics. These include the preparation and management of face to face contact with students, quality management from student interviews to committee work and the Service User's role in research engagement.

The following sessions will run from 10.15am-1.15pm.

Date	Event
7 March 2014	Preparing for and managing face to face contact with students
11 April 2014	Managing quality: From student interviews to committee work
13 May 2014	Engaging in research: The Service Users' role

To book your place on any of these sessions, please contact: Mandy Walsh
E-mail: m.walsh@hud.ac.uk

If you would like to find out more or have any questions, please contact Janet Hargreaves
E-mail: j.hargreaves@hud.ac.uk
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Service User involvement in Social Work BSc(Hons) and Social Work MSc courses

Within the Division of Social Work there are many examples of the fantastic partnerships that have been established with Service Users and carers. One of the most significant contributions lies in the willingness of many Service Users and carers to share their experience of what it is like to be a Service User.

The Huddersfield University Group (HUG) from Bradford is a lively group of older Service Users who form an intrepid group of interviewees on whom the students can practice their interviewing skills. This forms part of the assessment for a module within the first year of Social Work BSc(Hons) and Social Work MSc.

Each student is given a short biography about a member of the group who they will then interview. This involves formulating appropriate questions, organising the interview, meeting and greeting the interviewee and being responsible for the whole process, including video recording. The HUG member participating in the interview then provides feedback to the student on their interviewing skills.

The group also share their experiences, which helps them develop a greater insight into Service User's lives, perhaps shattering a few stereotypical images on the way.

Judith Oliver, Senior Lecturer from the Division of Social Work

Creating the right impression: Service Users presence at Nursing induction by Carl Covill

The induction for student nurses is an important event at the University as it sets the tone for the next three years of their professional training.

As Year 1 Leader in Nursing and organiser of induction events, it was extremely important that students remember why they are becoming nurses. Four members of the Service User and Carer Group were invited to attend, where they provided reviews of why it is important to remember the person you are caring for, ensuring they understand individuals are unique entities in which they will have issues that are specific to them and their families.

The four members of the Service User and Carer Group also provided overviews of why it is important to engage and listen as a professional and explained the benefits of person centred care.

The students were enthralled in the session and actively listened, questioned and discussed with the group their experiences and the issues around good and bad care.

Other members of the group who attended and were involved in the curriculum development of the course, also shared their unique insights and experiences with the students.

The programme was well delivered and positively received. Due to this success, it is hoped they will continue their involvement throughout the student journey.

Carl Covill, Senior Lecturer and Year 1 Leader in Nursing

A student's view: volunteering with the Human and Health Sciences Public Partnership Group



“I am a third year student on Health and Community Studies BSc(Hons), who had the opportunity to undertake my placement with the Service User and Carer Group, within the University.

“This was fulfilling and rewarding as it enabled me to gain an immeasurable amount of knowledge and experience, which I could not have been taught in lectures, or found within books and journals.

“The most rewarding part was the people I met, they were all really interesting and I plan to remain on the group when my placement finishes. My confidence and ability to address difficult situations has developed which has improved my leadership and management skills.

“I would recommend other students who have the chance to join, to seize the opportunity as they won't be disappointed, they will find it very rewarding.”

Karen Michelle Williams, third year student,

What works? Service Users and carers role in students' clinical learning

A Service User forum in the Podiatry Clinic originally requested feedback to determine the impact Service Users and carers had in the students' clinical learning of Podiatry.

One group of healthcare students were chosen to participate in a questionnaire that asked them how their learning was affected by the involvement of Service User (patient) and carers in the clinic environment.

The questionnaire was divided into two parts. Part one asked about the Service Users' role in supporting their clinical learning at both University clinics and in NHS settings. Part two asked about the patient's role as expert patients in student's learning about the conditions.

The summary report showed an overwhelming declaration of how important Service Users and carers are in supporting clinical learning of the students.

“Working with patients has made a huge difference to my learning”

“Patients are the most important part of any healthcare course”

“To understand conditions you need to speak with those who live with the condition or their carers and families”

“Working with patients has enabled application of knowledge”

The report highlighted a difference in the responses regarding Service Users in different clinical settings.



“Patients at the University have wider knowledge and are more prepared to talk about their condition, medications and the effects of living with their conditions”

“Fewer patients in the community clinical settings had knowledge of their conditions and were less likely to talk about them”

This initial review provided very positive feedback of the Service User's role in supporting student's learning.

A similar study may be undertaken in the future with other healthcare students to further investigate the influence this important group of people have in the clinical learning of our healthcare students.

Dr Chris Davies, Divisional Leader for Podiatry

A Service User's view: Getting involved after life changing treatment

"I was diagnosed with tongue cancer in September 2007, which is where my journey began. This was the first time I had used the NHS, the outcome was amazing and I have been free of cancer now for six years.

"Afterwards I decided that I wanted to use my experience to help others. I was invited by the Yorkshire and Humber Postgraduate Deanery of Dentistry to deliver a talk about 'The Patients Journey'.

"This helped Dental Nurses and Dentists to understand the journey of the patient after they are referred. I received very positive feedback from the talk and hope that as a result they undertake a mouth cancer check for every patient they see.

"I have now embarked on an association with University of Huddersfield and have joined the steering committee of the Public Partnership Group.

"I am also delivering a talk to Nursing Students on communication, through the eyes of a patient, helping to put real life situations into context. I look forward to doing further talks in the future."

Christine Raw, Service User

Getting involved with research from design to publication

"Five years ago I became involved in a research project, alongside Steve Lyons, a lecturer at University which looked at emotional intelligence in the recruitment of mental health nurses. We involved outside agencies to recruit other Service Users and carers and held a focus group. A small group of committed people was formed who worked equally to achieve our goals.

"We were all involved in the project from the onset right through to the publication of our work. Many ups and downs were experienced but we all remained passionate about the project and stayed on track with our aims. I personally felt I was involved throughout each process, which included: researching, assessing students, training Service Users, disseminating information, addressing issues which arose along the way, developing our own assessment tool and final publication. We all brought different skills to the table and as things progressed, my confidence grew knowing my contributions were important and of value.

"An article was published in the Nursing Standard Journal in June 2013 which was a proud moment for us all. It brought welcomed congratulations and also increased the interest surrounding our project. A number of lessons were learnt through undertaking the project, some of which will be very beneficial for future research. Through the experience, I now have a deeper interest in research and I hope to use my skills to assist other members of the Human and Health Sciences Public Partnership Group and wider Patient and Public Involvement (PPI) groups to become more involved."

Elaine Powell, Human and Health Sciences Public Partnership Group member

Spotlight: A life of involvement

Frank Adams, long standing podiatry clinic user

“You may be wondering what life is like when you have a disability. Imagine not being able to do the simple things in life. How would you feel? How would you like to be treated? Here are some of my life events which I’m sure some of you can relate to...

Age 3

“At a very young age I had Polio but I have vague memories of it. I only remember being on an isolated ward with other children with polio or those suspected of it. The GP said the reason it developed was due to ‘low immunity’. I had many operations which were of benefit to me and were all decided by my parents. However, no medical records were passed on which enabled me to look back.

“Polio is an infectious disease caused by one of three types of polio virus, entering your body through your nose or mouth and develops in your throat and intestines. The polio virus may go on to invade your central nervous system, destroying or damaging the nerve cells (motor neurons) that control your muscles.

Childhood

“As I was growing up my parents wanted me to attend a ‘special school’. I attended for two years but when I refused to go back, I went on to an ordinary school instead. I remember being isolated by other children as they thought I was ‘different’ from them. I left school at 16 and started office work which I did not particularly enjoy doing, but was forced into it by the school and my parents.

Adolescent

“The teenage years are particularly hard for most people as changes take place. In my

case, the other boys used to think they were superior to me and did not like girls talking to me. Although I admit it myself I got on better with women who saw me as no threat, but unfortunately this led to relationship issues.

Adult

“As years went by I also had family problems, such as my children having negative comments directed at them about me. Unfortunately, this is how disability is portrayed within the media and other arenas. Even with my disability however, I was very athletic and active as I used to go swimming and had various interests including playing music, reading, nature and even though I can’t continue with these hobbies, I still feel that I had high self-esteem as I am confident and a very assertive person.

Late 40s

“I was diagnosed with Post Polio Syndrome (PPS) in the mid 90’s, which is a neurological condition caused by a highly infectious virus and likely to occur in people who have had polio. After a long time without any significant change in their condition, people may develop new symptoms of increasing weakness, stamina problems, fatigue and pain, the disease can be fatal. At first I experienced difficulty in doing everyday tasks which I thought were due to age but soon realised that this was not the case. I was referred to St Thomas Hospital in London but found it too far to travel with the amount of energy it needed. I didn’t really have anyone to talk to about this condition as there was not much awareness of PPS although I began to find ways to access information about it.

“The condition progressed in many ways as I got tired and fatigued. I also had accidents

especially whilst walking and the falls were painful. I developed sleep apnoea where I had difficulty breathing during the night, this is where there are abnormal pauses in breathing while sleeping. After this development, I had to start using a bi-pap ventilator, a machine which maintains a certain amount of air pressure within a mask I that I wear whilst sleeping. This keeps the airways open, allowing me to breathe easily.

“Throughout various operations in my life I have gone from using crutches, callipers, walking sticks to wheelchairs and I have also got my own personal adapted vehicle, as well as an adapted flat with fitted railings, ramps and a wet floor shower area.

“One thing I find frustrating is waiting for things to be done for me. There are simple things in life I miss doing such as checking my clothes in the mirror to see how I look, going to the toilet and opening car doors all by myself.

“The most frustrating part of my life is being restricted as to where and when I can go due to poor access and restricted facilities. These include simple things like trying to find accessible venues to eat, drink and for entertainment or going into the country for a walk and looking at wildlife.”

Getting involved

“Before I started working with the University I used to work in a Kirklees Social Services department, designing and setting up projects to promote equality and independence for disabled people. I was then contacted through work by the University and became involved in projects with nursing, social work and podiatry students, as well as staff, which I thoroughly enjoy doing. You might be wondering what the reasons are as to why I do this voluntary work, the answer to this question is the sense of fulfilment I get from giving back my own knowledge and experiences to the community.

“I feel that there are many ways the University can improve their accessibility and services. The layout and structure of the buildings are really important to consider, as well as simple things such as where resources are placed. The library facilities are also essential to think about, for example, leaflets which are designed and printed for the library using small font sizes with background colours that are difficult to read.



“I think that these ideas should be developed for the future, they should challenge the established way of diversity and most importantly remove barriers to education and life.”

Continued...

The impact of involvement

“During my life I have had many different experiences, both good and bad. I also know what it feels like to be abused, which takes place in the contemporary community by different races and cultures, although some people may refuse to believe this. I really feel dismayed by the ignorance I witness towards disabled people and think people should realise that those with disabilities are not invisible.

“They should all be treated as equals, yet there are many compromises that still need to be made. However, it is not all doom and gloom as there are also positive experiences that I have had. I feel that this journey has made me become much more confident, patient and motivated towards making a difference.

“I am a good communicator but also enjoy my own company. I have been told by people that I am easy to talk to, as I take the time to listen, which is why I enjoy the work I am doing.

“The best advice I can give is to think positive, live life to the fullest, communicate with a smile or interested expression, using good manners, as this really helps with interpersonal communication and finally have no regrets.”

Frank Adams, Service User (co-produced by Mariam Karim, Health and Community Studies BSc(Hons) student).

Research update: The Agency of Service User and Carer engagement in Health and Social Care Education

Christine Rhodes, Head of Undergraduate Nursing is working on her PhD looking at ‘The Agency of Service User and Carer Engagement in Health and Social Care Education’. The following abstract outlines the scope of the work she is undertaking.

Service User and carer involvement in health and social care education has gained momentum over the last two decades, largely driven by consumerist and democratic ideologies. This is reinforced by the health and social care regulatory bodies including the Nursing and Midwifery Council (NMC) and the Health and Care Professions Council (HCPC).

The aim of Christine’s thesis is to explore the agency of Service User and carer engagement in health and social care education. This is achieved by investigating key stakeholder perspectives presented through a series of eight papers published in peer review journals that follow a systematic exploration of methods of enquiry. In addition a commentary draws the papers together and locates them within an overarching theoretical framework.

The resulting body of work demonstrates a coherent approach that draws on underlying philosophies and theoretical underpinnings that displays contribution to knowledge. This is delineated into distinct sections with contribution to the literature with new findings, relating to original perspectives from key stakeholders on the benefits and risks associated with user involvement and examples of what does and does not work.

Additionally, the location of findings within the theoretical framework, with the offer of an alternative ‘model of involvement’ that acknowledges the multiple facets of user

involvement. Further, the location of findings in the current research literature reinforces and extends the evidence base.

Overall this work adds to the refinement and development of the theory of user involvement in health and social care education with recommendations for practice. This includes adopting a more radical 'post engagement' state in pursuit of a true partnership approach with genuine equality and respect, with equal status of all the agents.

There is a pressing need for additional research to further substantiate the benefit of user involvement for all parties concerned in order for user involvement to take its place as a core component of health and social care education.

Christine Rhodes, Head of Undergraduate Nursing and PhD student.

Publications and presentations

You may be interested in the following publications and presentations related to Service User involvement, which Service Users and members of staff in the School have been involved with in recent years.

Lyon, S.R. Trotter, F. Holt, B. Powell, E. and Roe, A. (2013) Emotional Intelligence and its role in recruitment of nursing students, *Nursing Standard*, 27, 40, 41 – 46

Rhodes, C. (2013) Service User involvement in pre-registration children's nursing education: The impact and influence on practice: A case study on the student perspective, *Issues in Comprehensive Pediatric Nursing*, ISSN 0146-0862

Adams, F. and Holt, C. (2013) The Service

Users experience of involvement in the design, delivery and evaluation of the curriculum, *The Role of Professional Regulatory Bodies in Patient, Carer and Public Involvement*, 12 February 2013, Leeds, UK

Rhodes, C (2013) The lecturer experience of impact on a student's learning and practice from involving patients and carers in the delivery of the curriculum. *The Role of Professional Regulatory Bodies in Patient, Carer and Public Involvement*, 12th February 2013, Leeds, UK

Padgett, K. Rhodes, C. Lumb, M. Morris, P. Sherwin, S. Symons, J. Tate, J. and Townend, K. (2012) What matters to users of services? An explorative study to promote shared decision making in health care, *Health Expectations*, ISSN 1369-6513

Rhodes, C. (2012) User involvement in health and social care education: A concept analysis, *Nurse Education Today*, 32 (2), pp. 185-189, ISSN 0260-6917

Dearnley, C. Coulby, C. Rhodes, C. Taylor, J. and Coates, C. (2011) Service Users and carers: Preparing to be involved in work-based practice assessment, *Innovations in Education and Teaching International*, 48 (2), pp. 213-222, ISSN 1470-3297

Hemingway, S. Stephenson, J. and Allmark, H. (2011) Student experiences of medicines management training and education, *British Journal of Nursing*, 20 (5), pp. 291-297, ISSN 0966-0461

Rhodes, C. and Nyawata, I. (2011) Service User and carer involvement in student nurse selection: Key stakeholder perspectives, *Nurse Education Today*, 31 (5), pp. 439-443, ISSN 0260-6917

