

Wednesday 28 October 2015

Event report



Introduction

This interactive and dynamic event brought together people from across England and Wales who coordinate service user and carer involvement in Higher Education in health and social work programmes.

The day included opportunities to engage in solution focused workshops to identify challenges and solutions to inform and develop effective involvement in our own field of practice and to explore and share ideas and resources.

Participants were encouraged to identify themes or challenges they wished to explore during the day and to identify tangible solutions. This report seeks to capture some of these discussions and solutions.

The event was attended by people representing the following universities:

- Ruskin College
- Southampton Solent University
- University of Kent
- University Campus Suffolk (UCS)
- University of Bristol
- Bournemouth University
- University of Wolverhampton
- University of Southampton
- Buckinghamshire New University
- Lancaster University
- Kingston University
- University of Sunderland
- University of Bedfordshire
- University of Cumbria
- University of Surrey
- University of Greenwich
- University of West London
- University of Portsmouth
- University of Huddersfield
- Sheffield Hallam University
- University of Derby
- University of Hertfordshire
- Middlesex University
- Brunel University London
- University of Birmingham
- University of the West of England (UWE)
- Cardiff University
- University of Northampton



Participants coordinated involvement for a range of programmes. Whilst some were employed as coordinators, others organised involvement as part of a wider role.

Programmes included:

- Social work
- Pharmacology
- Radiography
- Adult nursing
- Child and young people's nursing
- Mental health nursing
- Learning disability nursing
- Psychology
- Physiotherapy
- Operating department practice (ODP)
- Occupational therapy
- Paramedic science
- Patient and Public Involvement (PPI) in research

Themes generated from the sculpt session 'what does service user and carer involvement mean to you?'

- Meaningful collaboration between service users, carers, academics and students
- Valuing diversity and different perspectives
- Enabling experts by experience to have a voice and be heard
- Creating opportunities to stand in someone else's shoes
- Recognising and valuing the fluidity of roles and identities



Questions generated from the workshops were merged to create 22 key questions:

- How can we move away from service user and carer involvement being academic led?
- How can we evaluate service user and carer involvement in teaching?
- How are service users and carers valued?
- How political or strategic must we be?
- How can we disseminate best practice?
- How do we manage a lack of time, resources or lack of interest from other colleagues?
- How do we promote real service user and carer involvement and avoid tokenism?
- How do we instil in all staff that it is everyone's responsibility and not one person only
- How can we involve people in innovative ways
- How appropriate is it to use service users and carers in role plays or simulation of real life
- How do we ensure that the main focus is on the service user experience?
- Do we pay service users and carers for their time?
- How do we manage when people don't do what they say they will do?
- How do we translate policy into reality (avoid lip service)
- How do we effectively prepare students and service users and carers / contributors for involvement (emotional involvement)?
- How do we measure the outcome / impact?
- How do we recruit and keep younger members / hard to reach groups / a diverse membership
- How do we minimise cherry picking?
- How do we manage ethical dilemmas
- How do we ensure that support and training is of benefit to service users
- Do we need different terminology (experts by experience)?
- how do we safeguard people we involve

Service user, carer and students perspectives:



What does involvement mean to us and what should coordinators not lose sight of?

BU students from adult nursing, physiotherapy and social work said:

- hearing people's stories is a reality check
- first-hand perspectives help us make sense of theory by relating it to real experiences
- it's meaningful when you get feedback from a service user
- it reminds me of what impact our intervention can have on someone's life (good and bad)
- sharing of a lived experience raises awareness of issues around disadvantage. It enhanced my learning journey
- People's experiences challenge my preconceived ideas and assumptions. It brings reality
- you cannot learn about human emotion from text books...it helps you to connect when you're out there (in practice). It helps develop emotional resilience
- person centred practice – everyone is an individual and may have different goals...Hearing their side of things, unfiltered feedback and authentic reporting
- people are experts in their own conditions – their opinions are really valid as they live 24 hours a day with this

What not to lose sight of:

- Opportunities to consult and ask questions of service users and carers in small, more informal groups.

- Having some de-brief time once the service user or carer has left to reflect on the emotional impact of their experiences / the role play or activity – not having to rush straight to another lecture



BU Carer and service user partnership (CSUP) members said:

- I can help inform the next generation of health and social work professionals
- I feel genuinely valued for the experiences and perspectives I can share
- I do think I offer something that academics can't
- I get so much out of it too – confidence, I learn a lot, I feel it's important, it gives me a role and a status
- I like being able to say to my family that I'm going to do my work at the University
- It is amazing when we get the written feedback from students about what they got from the session / activity
- I trained as a social worker although am now a service user and a carer so I can see it from both sides
- I had to stop my nurse training here due to my health. It means I can still be involved
- The students are so open and keen to learn from us
- I like that it's not just about sharing our stories but also giving our opinion

What not to lose sight of:

- Life can be very busy when you use services or are a carer for someone. We need notice and preparation
- We might need support and time to de-brief after a session
- We might not feel confident when doing something new
- Sometimes we might not feel confident to volunteer for things even when we want to or because we don't know if we will be good at that. We might need your help to find what we can do and your encouragement

Ideas and solutions

We engaged in discussions to share ideas and identify solutions to the questions, issues and challenges raised. There were many examples of good, creative and innovative practice which have been listed here as a generic list of ideas which can be used to respond to multiple challenges:

Recruitment of service users and carers:

- Look at sharing resources across a school or faculty
- Ask students to promote the group whilst on placement
- Harness lines of communication between academia and practice e.g. lecturer practitioners
- Meet with potential members outside of university – you go to them
- Engage organisations and services who can be involved as a group
- Work out 'who is' the local community to ensure that your recruitment reflects this diversity
- Use social media, word of mouth
- Service user and carer involvement is an ethos, not a specific group of people
- Hold an event e.g. a carers day – provide goodies and food, share and capture experiences which can be used again e.g. video diaries, audio recordings

Supporting service users and carers:

- Support volunteers by having an annual review process
- Provide payment and perks e.g. training, use of library and IT facilities, meeting rooms, certificates for training and CPD
- Establish safeguarding arrangements – know the adult safeguarding policy, emergency contacts, academic present during activity, book people through organisations who will provide support and share the work, encourage service users and carers only to answer questions they are comfortable answering – it's okay to say 'I'd rather not respond'. Meet and greet / have a de-brief over a coffee following the activity
- Provide a welcome / induction pack. Include information on impact of any payment on benefits or identify that it can have an impact and provide contact details / links to benefits advice.

- Make it okay for people to dip in and out of being involved or contribute as a one off
- Create opportunities for co-support or mentoring within the group and for regular meetings
- Explore opportunities for service users to meet with those involved at other universities
- Provide specific preparation, guidance and intended learning outcomes for each activity
- Ask students to complete a short evaluation at the end of each activity to identify what they gained from the session. Ask questions which generate reflection and goes beyond 'I loved the session'. Also helps to reinforce students' own learning. Share with the academic and the service user.
- Ask the service user(s) and carer(s) to complete a short evaluation at the end of each activity to identify what they gained and what they thought of the session. Use to improve and develop practice and share with the academic

Developing involvement in your place of work:

- Be creative in how you involve – assessing students work, admissions, developing case studies, input in teaching / lectures, curriculum design, feedback on students practice, preparation and readiness for practice, communication and professional skills units / modules
- Start small and then build ideas from initial involvement
- Make use of external resources e.g. online forums, published narratives and stories, podcasts, films, broadcasts. Set up conversations via skype instead of service user or carer coming into the university
- Add autobiographical content e.g. books and films to reading lists
- Link to national themes and make use of those resources e.g. Mental health week, carers week
- Link to organisations particularly for hard to reach groups and children e.g. a young carers group, children's centre, school
- Evaluate outcomes to justify (further) resources – link to key performance indicators or professional standards e.g. DoH, CQC, NMC, HCPC, professional colleges - evidence for why and how involvement is used in your service – evaluate the impact
- Create a toolkit and / or good practice guide to share with colleagues
- Share this conference report with colleagues and hold a meeting to discuss your ideas

Support for coordinators

- Join the DUCIE network (Developers of User and Carer Involvement in Education, Jill Anderson) or LEN (Lived Experience Network, Jools Symons)
- Find like-minded people in your organisation
- Follow up contacts and potential support and collaborations from this event
- Access shared resources and materials

Pledges and actions were identified to take this work forward collectively and as individuals. Collective next steps include:

- Add your university's details and information on involvement to the DUCIE network website (via Jill Anderson)
- Don't reinvent the wheel - Send copies of resources you are happy to share to Mel Hughes e.g. welcome packs, training materials, booking forms, evaluation forms, involvement strategies, so these can be shared across the mailing lists, networks, blogs and BU website as examples of good practice
- Share links to useful websites, reports, resources, articles, papers

Individual plans and actions identified in the workshops and evaluation forms:

- Write a report of the conference to share with colleagues
- Arrange a meeting with colleagues to discuss ideas / critical discussion about how to work together x 3
- Check out with existing service users / carer / experts by experience, their emotional responses to involvement activities
- Identify and use videos and podcasts
- Evaluate service user contributions
- Review the involvement strategy
- Develop diversity training
- Continue conversations with contacts from today and others in HE x 4
- Develop a logo
- Recognise the many ways that people can be involved
- Work on increasing awareness of involvement across own university
- Check out existing practice across the university
- Add links to films and autobiographies with service user and carer perspectives to reading list for each module
- Formalise the involvement of service users and carers in my department
- Look at improving systems for recruiting and supporting service users and carers x 2
- Ask for more hours of my workload to be dedicated to involvement
- Identify opportunities for our service user network to network with those involved in other HEs
- Goal to achieve more involvement activity across the board x 4
- Set up a blog / use social media x 2
- Explore options for involving service users in assessing students' work
- Explore options for involving children and young people x 2
- Compile a toolkit of resources / good practice guide
- Make contact with contracts and finance to look at budget / payment and recruitment of specialist worker x 2
- Follow up new ideas for recruiting service users
- Involve service users in induction process and preparation and readiness for first placement
- Be more enthused!

Links to resources identified by participants

- The patient patient blog <http://thepatientpatient2011.blogspot.co.uk/>
- British Medical Journal Patient perspectives <http://blogs.bmj.com/bmj/category/patient-perspectives/>
- Health Talk online <http://www.healthtalk.org/>
- Lived Experience Network (LEN) <http://www.alps-cetl.ac.uk/len.html>
- Shaping our lives network <http://www.invo.org.uk/find-out-more/invodirect-org/shaping-our-lives/>
- For a memorandum of understanding between academics and service users <http://www.eassw.org/>.
- For the blog mentioned by Abyd on the day: <http://blogs.cardiff.ac.uk/abyd/>

And finally.....

Thank you for all of you who participated on the day and have been in touch since for your enthusiasm, creativity and productivity. Our approach to collaboration is that we all take from the event what we need and develop the networks that work best for us. We are happy to support and facilitate or for you to take the lead. We are looking forward to some exciting collaborations ahead.

There was a clear interest on the day and within the evaluation forms for future events, particularly if following up on progress made with actions identified in this report or if focussing on specific types of involvement in admissions, assessment, teaching, research and skills. We are happy to arrange another event next year to focus on these specific areas (this is our pledge!).

Happy involvement

Dr Mel Hughes, Academic lead for service user and carer involvement

Angela Warren, service user and carer coordinator for NMC programmes and research at BU

Pete Atkins, service user and carer coordinator for HCPC programmes and wider engagement at BU

Appendices (please feel free to adapt)

Bournemouth University CSUP member registration form

Bournemouth University CSUP Booking form

Bournemouth University CSUP student evaluation form

Bournemouth University CSUP service user and carer evaluation form

Name		
Address:		
Contact telephone:		
E-mail:		
ICE number: (In case of emergency)		
Name of person and relationship to you:		
Preferred method of communication		
Are you a	Service user <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/>	
What are your areas of lived experience? Tick all that apply		
<input type="checkbox"/> Learning disability	<input type="checkbox"/> Physical Disability	<input type="checkbox"/> Children/young people services
<input type="checkbox"/> Mental Health	<input type="checkbox"/> Substance misuse	<input type="checkbox"/> Other (please state)
<input type="checkbox"/> Carer of an Adult	<input type="checkbox"/> Carer of a child	
<input type="checkbox"/> Carer of an older person	<input type="checkbox"/> Care leaver	

Please add further details

These are the areas where members have been involved. In which areas would you like to be involved (as and when, opportunities arise)?

Talking about your experience to groups of students

Writing a narrative of your experience to be used as a learning resource.

Assessment of students

Being involved as part of a research team e.g. planning and undertaking research

Being involved in the interviewing and selection process for students

Being filmed giving a talk to use as a learning resource.

Involvement in the design of courses

Please indicate if you would require any of the following to enable you to be involved.

Help with access to buildings

Personal assistant to accompany you.

Other

Hearing Loop

Computer

Please tell us about anything else we need to know to ensure that you have what you need and feel safe and supported whilst undertaking involvement activities

Please note: a member of staff will always be present

Do you have any dietary requirements or food allergies/sensitivities that we need to know about?

Yes No

If yes, please give details:

Your travel expenses (plus parking) will be reimbursed in cash, on the day you attend. Please retain any receipts and tickets.

Most activities will take place at the Lansdowne Campus (Christchurch Road)

What transport will you (mostly) use?

- | | |
|--|---|
| <input type="checkbox"/> Own Car | <input type="checkbox"/> Public Transport |
| <input type="checkbox"/> Will require a taxi | <input type="checkbox"/> Cycle/Walk |
| <input type="checkbox"/> I would require a parking space | <input type="checkbox"/> I have a Blue Badge (Disabled parking) |

Payment for your time will be by cheque The cheque can be made payable to yourself or an organisation of your choice. Please state to whom you would like the cheque made.

.....

N.B. The recipient of the payment has responsibility for the tax implications.

Date: Signature.....

Do you use any of the following:

i Phone <input type="checkbox"/>	i Pad <input type="checkbox"/>	Skype <input type="checkbox"/>
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Which of the following groups contains your age?

Under 18	<input type="checkbox"/>	46 - 55	<input type="checkbox"/>
19 – 25	<input type="checkbox"/>	56 – 65	<input type="checkbox"/>
26 – 35	<input type="checkbox"/>	Over 65	<input type="checkbox"/>
36 – 45	<input type="checkbox"/>	Prefer not to say	<input type="checkbox"/>

Ethnic group: How would you describe yourself?

White	British	<input type="checkbox"/>
	Irish	<input type="checkbox"/>
	Other white background	<input type="checkbox"/>
Black/Black British	Caribbean	<input type="checkbox"/>
	African	<input type="checkbox"/>
	Other Black background	<input type="checkbox"/>
Asian/Asian British	Indian	<input type="checkbox"/>
	Pakistani	<input type="checkbox"/>
	Bangladeshi	<input type="checkbox"/>
Chinese or other Ethnic Group	Chinese	<input type="checkbox"/>
	Other	<input type="checkbox"/>
Mixed Heritage	White and Black Caribbean	<input type="checkbox"/>
	White and Black African	<input type="checkbox"/>
	White and Asian	<input type="checkbox"/>
	Any other mixed background	<input type="checkbox"/>
Prefer not to say		<input type="checkbox"/>

Please use this space if there is anything else you wish to include on this form

Please return this form to either of the Service user/Carer coordinators:

Angela Warren
awarren@bournemouth.ac.uk
01202 962022

Peter Atkins
patkins@bournemouth.ac.uk
01202 962198

Room R709 - Royal London House
Christchurch road
Bournemouth
Dorset BH1 3LT

This form is for members of academic staff to request the involvement of service users and/or carers to contribute to their programme.

Requirement (as much detail as possible. What experience does the person need to have, and what do you want them to do? Will it be the whole group/small groups, etc?)			
Unit of Learning			
Purpose: What is the context of this session? What are the Intended Learning Outcomes?			
Venue Full address			
Date & Time			
Co-ordinator contact			
Academic Lead			
Student year group		Number of Students	
Additional Information			

For Office Use only

Name of Service User or Carer	
Attendance confirmed via:	
Car Parking booked at:	
Co-ordinator to greet and administer payments	
Risk Assessment Completed	<input type="checkbox"/>

Course		
Date		
Unit		
Year Group		Session
Service User/Carer		
What did you learn from this session?		
What could have been done differently?		
Comment(s) for the service user/carer		



Bournemouth
University

HSC Carer and Service User Participation: Service User/Carer Feedback

Course		Academic
Date		
Unit		
Year Group		Session
Your name		Co-ordinator
Was the Booking Form useful?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Comments :		
 Comments on the practical arrangements:		
 How did you find the students?		
 Was the lecturer supportive? Yes <input type="checkbox"/> No <input type="checkbox"/>		
What could he/she have done differently?		
 How did you feel at the end of the session?		