

### Public Involvement in Education and Research Partnership

Annual Report 2022-23 September 2022-August 2023

# **Flipping the power:** developing inclusive public involvement in education and research



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Message from the academic lead for the PIER partnership



partnership. Every year the with an opportunity to look back at our achievements and impact and to share some highlights from our year. This report covers PIER activity from September 2022 to August 2023.

When thinking about the focus for this year's report, I recognised that we now have a much sharper focus on health, social and economic inequalities in society and the role of lived experience expertise in addressing this. The inequalities amplified by Covid, and the continuing impact of the cost-of living crisis on our members and community partners has led us to consider our responsibility within PIER to create a platform for people with lived experience to have a voice and be heard. We can only address inequalities by addressing this power imbalance. Our approach has been to 'flip the power' by creating opportunities for people with lived experience to lead and direct the focus and nature of PIER activity. This year's report shines a spotlight on some fantastic examples of people with lived experience doing just that, from Disabled people conducting research to better understand Disabled and neurodivergent people's access to cancer services; research with carers on the impact of the cost-ofundertaking their own research with PIER's mentoring and support to address inequalities such as older people's experiences of Hidden Hunger. It includes PIER members co-designing and delivering webinars, workshops, training and coaching sessions to researchers across the region on how to engage marginalised communities and to create opportunities which are more inclusive. It has involved 159 separate educational activities with students across the year, co-designed and facilitated by PIER members and

The PIER partnership is a collaboration between people with lived experience, community organisations, academics and students at Bournemouth University. As experts by experience, we bring unique perspectives, knowledge and insight to health and social science education, research and practice, leading to improved outcomes for all involved.

partners, ensuring that lived experience expertise and the realities of everyday life are at the heart of BU health and social care education. Having a platform to be heard has enabled PIER members this year to share their expertise beyond BU including nationally through contributions to book chapters, to World Social Work Day, at a national conference and internationally when bringing together highlighted in this year's report.

Reflecting on this past year, we recognise that opportunities for PIER members to be involved in designing activities from the start has gone from strength to strength. Creating opportunities for people with lived experience, community partners and BU academics and students, to work together in equal partnership for equal benefit has made a significant positive contribution to the BU community. There is strong evidence that this partnership approach is enabling us to more effectively address issues of equality, diversity and inclusion in our education and research activity and ensures our research and education is relevant, of high quality and has a positive impact.

Our flipping the power approach involves harnessing lived experience expertise, making space for a more diverse range of voices, creating opportunities and removing we have invited PIER members, community partners and collaborators to consider the impact of our involvement in achieving these collective goals and to reflect on the benefits to them. I would like to thank each and every one for making this happen. It has been such an exciting year, bring on the next one!

#### Professor Mel Hughes

Professor of Social Work Academic Lead for the PIER Partnership

# About us: Our goal, values and approach

The PIER partnership is a collaboration between people with lived experience, community partners, academics and students at Bournemouth University. As experts by experience, we bring unique perspectives, knowledge and insight to health and social science education, research and practice, leading to improved outcomes for all involved.



### **Our goal**

For those who are most affected by health and social inequalities to lead the way in shaping responses and improving outcomes.

### Our shared values

The BU PIER partnership is underpinned by our shared values and goals of humanised and relationship based models of collaboration. Our work is based on respect and meaningful engagement where everyone involved feels valued and respected.

### **Our approach**

To involve people with lived experience as consultants; reviewers; researchers; facilitators and assessors due to the expertise they have and the perspectives they can share.

To develop inclusive models of collaboration in education, research and practice which are based on parity of involvement; giving people a voice; and enabling a wide range of people to participate in ways which work best for them.

To broaden the range of voices collaborating in research, education and practice; in particular, marginalised and seldom heard groups.



# A word from our PIER officers



Angela Paget PIER officer (developing involvement in Nursing and Midwifery Council

programmes.

me have been:

Microsoft Teams.

develops in 2024.

Manager at BU

Reflecting on the last academic year made me think that relationships are at the heart of all we do in PIER. Our work is all about people; connecting people to design, deliver and evaluate educational activities, gathering people together to shape a research project that will have impact, and allowing people to be who they are; bringing their many skills and attributes to enrich the life and work of BU.

This last year has seen members of PIER being involved in a number of Continuing Professional Development (CPD) courses including, Independent & supplementary Prescribing, Return to Nursing Practice, and Advanced Clinical practice. Some students questioned what they would gain from 'patients' as they are currently in practice, but came away saying:

"I came in sceptical about what I would gain but am honestly taking away a lot.

I am refreshed, reminded and renewed - a very good use of time."

When asked what they hoped students would learn from them, PIER members spoke about the importance of listening and treating them as a [whole] person, not defining them by their condition.

Academics have described the input from PIER as something that "cannot be gained through books and a deep and valuable insight into patients' experience."

It has been a delight to hear stories of how PIER has been life changing for some members and for others, how they feel that they have something to give in spite of having lost their career due to illness.

I have loved seeing PIER expand and develop in the last year. We've gained many new people who have been involved in research projects and witnessed more established members grow in confidence, by becoming coapplicants on research bids, co-design and deliver training and providing input into our new payment policy. Working with such a great team and seeing the positive impact of our work are the reasons I love my job!

at the end of this year with Social Work and Operating Department Practice (ODP) programmes on preparation for re-validation in 2024.

#### Pete Atkins

PIER Officer (developing involvement in Health and Care Professions Council (HCPC) & Social Work England programmes)

2022-2023 for me has been about increasing the range of PIER members and organisations we work with. providing meaningful training and support to our members, and supporting the Academics and students we work with across all our

#### Some of the highlights of the year for

• Supporting Chris Pitt from the University in providing two training sessions for PIER members at the University on using Zoom and

 Further developing our contact with Academic colleagues at Western Norway University of Applied Sciences bringing together PIER members both in Norway and Bournemouth and Academics from Social Work and Operating Department Practice (ODP) programmes (Ros Dray and Emil Sawadi) and Academics, Mariann Iren Vigdal and Tone Larsen from Norway to share positive practice experiences and see how this

• Widening the variety of outside organisations we work with • Establishing a meaningful link up with YOU Catalyst with Layne Hamerston, Community Partnership

• Contributing to a book chapter on Social Work Practice with Adults | SAGE Publications Ltd along with other PIER members which has been published in conjunction with Dr Sally Lee and Dr Louise Oliver from the Social Work team in April 2023 Initial set up preparation discussions



Kate Jupp PIER Officer (developing involvement in research)

This has been my first year as part of the PIER team, and not only does the year seem to have flown by, we also seem to have achieved so much.

In my role to support and build the capacity of meaningful public involvement in health and social care related research across BU I have contributed to establishing the university's firm foundations for meaningful public involvement in research across all faculties.

This year PIER have continued to work hard to develop a culture of inclusive public involvement across all faculties of the university and to support the evolution of new and innovative ways of involving those most marginalised and seldom heard in health and social care research. The funding to support my position in PIER has really helped to accelerate this.

The highlight of my year has been being repeatedly witness to the transformative impact meaningful public involvement can have on the relevance, quality, and impact of the research project, to the understanding, confidence, and practise of the researchers, and to the lives of those contributing their lived experience expertise. This report includes just a few examples of the positive benefit of well supported and inclusive public involvement for all involved.

I am privileged be part of the PIER team and the wider PIER partnership. I have learnt so much in my first year from all those that I have collaborated with, and everyone I have supported to contribute their lived experience expertise to help influence, design and shape health and social care related research. I am looking forward to the year ahead and contributing my part in developing PIER's new plans and projects, and growing reputation for excellence.

# Our year in numbers 2022-2023

159	education activities we conducted
1,817	students we engaged with
51	PIER members involved
1,410	direct contact hours between people with lived experience and BU students and academics
39	academics we collaborated with
40	community organisations, trusts, local authorities and charities we collaborated with
53	research studies and funding bids we collaborated on
14	external events or conferences we presented at

### Just some of the activities PIER members have undertaken this year:

Influencing research ideas and design	Facilitating small student groups	Reviewing research funding applications	Co-delivering workshops and lectures	Simulation, role plays and conversations
Creating digital resources	Being community researchers	OSCEs (Objective Structured Clinical Exams)	Delivering training sessions	Revalidation advisory groups
Practice portfolio reading	Communication skills sessions	Community placements	Assessing practice presentations	Co-applicants on research bids
Co-desgning and delivering public involvement courses	Writing book chapters	Meeting with international partners	Co-authoring journal papers	Presenting at conferences

# **Collaborations with community partners**

As well as individual PIER members, PIER collaborates with a wide range of community partners in both education and research. Here, we list the 40 community partners PIER collaborated with in 2022-23 and share three examples to shine a spotlight on in this work.

### Community partners PIER collaborated with in 2022-23

4 Care Homes BCP Access to Food Partnership BCP Age Friendly Communities BCP Poverty Truth Commission Beyond Reflections Body Positive Dorset Bournemouth HealthBus Trust Bournemouth YMCA Carers UK Christchurch Community Partnership Christchurch Foodbank Communi–T Trans group Dorset Healthcare University NHS Foundation Trust **Dorchester Hospital Dorset Advocacy** Dorset Blind Association Dorset Clinical Trials Unit Dorset Community Foundation Dorset County Hospital Trust Dorset Innovation Hub

- Drop the Mask
- Escapeline
- Healthwatch Dorset
- Help & Care
- International Care Network (ICN)
- Lantern Project
- Lymphoedema & Lipoedema Support Group
- MS Centre Dorset
- My Time Young Carers
- Over the Rainbow
- RNIB
- Serendipity
- Social Work England
- Somerford ARC
- South Dorset Research Group
- University Hospital Southampton
- We are with you
- Wessex AHSN
- West Howe Community Enterprise
- Weymouth and Portland Community Research Network

### **Community partners spotlight**

We shine a spotlight on just three of these: Collaborations with Body Positive Dorset, Help and Care, and Weymouth and Portland Community Research Partnership.

### **Body Positive Dorset**



My name is Samantha Dawson, and I am the manager of Body Positive Dorset. We are a peer led charity supporting people living with or affected by HIV/AIDs. Our aims are to support and empower individuals going through an HIV journey, we also extend that same support to people affected by HIV and that can often be somebody's family members or partners.

Another important aim of the charity is to promote good sexual health, prevention of HIV and testing in various locations including schools, colleges, and universities. Education is a rewarding part of working for Body Positive Dorset and this has led us to have an excellent working relationship with Bournemouth University's PIER Partnership. We have been working with BU for about 8 years now and are proud to be a community organisation involved in PIER. Sharing the voices of the lived experience is a powerful tool and led to myself working with Mel Hughes on a book chapter for a social work textbook and presenting on this at a national conference in Glasgow, again sharing our lived experience of stigma and discrimination. It has also involved working with groups of nursing students, social work students and more recently with Occupational Therapy (OT) students.

For example, myself and my education colleague Par lead workshops with Nursing students and enjoy sharing up to date and relevant information that means that those students leave our sessions fully armed with the best information that will provide them with the skills not to discriminate against a person living with HIV in any type of healthcare setting. It is very fulfilling to see how we change some outdated stigma, and you can see that the students leave empowered and ready to address any discrimination that may happen in their careers going forward.

The relationships that we build with both BU and the students enable us to be a part of a wider community and that often means that students often want to get further involved with the charity as volunteers, but they also become advocates for our HIV community.



Samantha Dawson Manager of Body Positive Dorset

### Weymouth and Portland Community Research Network

I am Dr Siobhan Lennon-Patience, a BU Alumni and now Project Coordinator of the UKRI funded Weymouth and Portland Community Research Network. The Network is formed of three core community organisations based in Weymouth and Portland who have a long track record of support and engagement with a wide range of people in our local area. Our members are The Lantern Trust, a small independent charity offering support for people experiencing mental health issues, substance misuse, homelessness, disability, chronic health issues, domestic violence, learning disability and ex-offenders facing multiple social exclusion factors. Island Community Action, a charitable organisation contributing to the creation of a stronger more empowered, resilient, vibrant Portland; and STEPS Club for Young People a charitable organisation providing a full time youth centre offering a range of educational, developmental and preventative youth work opportunities for young people aged between 13-19 (up to 25 for those with additional needs).

Through the community network we are creating an ecology of research that is community-led and formalised into the research and innovation sector. This reverses the usual power relations in knowledge production. Key to this is the need to see real world impact of the research network's findings. Our work so far has focused on building relationships in readiness for future opportunities for knowledge production that is truly driven by community needs and aims. From the outset we have had a really fruitful working relationship with BU PIER, notably with Mel Hughes and Kate Jupp. We have worked collaboratively on funding bids, shared expertise and knowledge and our Network has also been able to provide speakers for PIER's Community Voice Webinars. Most importantly we have been able to forge links between community organisations in the Weymouth and Portland area and the work of BU. This has expanded the reach of BU PIER whilst giving our Network the opportunity to connect to the research ecosystem. We envisage that future collaborations will be mutually beneficial, strengthening local capacity for community engagement. We share the same ambition to enable experts by experience to be consultants, reviewers, researchers, facilitators, educators and assessors, making use of their expertise and the perspectives they can share.

# Help & Care

This year we collaborated with Help and Care on two community research projects, part of a larger piece of work called Whatever It Takes – Cancer Care for Everyone. The first project was What I Would Like to Say... which captured Disabled people's experiences of cancer services, using the BU PIER Community Researcher Model, to support the development of recommendations aimed towards improving the accessibility of these services.

My name is Kathryn Loughnan and I am the Director of Partnerships, Research and Influence at Help & Care.

This research project aimed to create new knowledge about the experiences of those from underserved communities building on insights from both service providers and service users to inform inclusive service design and delivery. It offers a case study of neurodivergent and Disabled people who experience challenges in accessing cancer services. This collaboration has led to a further proof of concept project with BU PIER, funded by NIHR (National Institute for Health and Care Research) working with the trans + community which we hope will form the basis of a range of projects tackling all types of inequality.

This project provided the first steps towards creating the partnerships needed so that service providers and users can work together to eradicate cancer inequalities. It built an understanding of how experience can lead to improvement through a carefully designed process where trust and a reduction of fear are managed.

Our intention to work with community researchers was not to replace existing co-creation activity, but to add something new. To ensure this approach worked, the

### **Community Voices Webinar series**

Part of our role within PIER is to use our platform to amplify seldom heard voices. In collaboration with the BU Centre for Seldom Heard Voices, we engage with many community groups, organisations, activists and campaigners who are conducting some wonderful work to promote inclusion and advance social justice across our region and further afield. To amplify these voices, we introduced a Community Activism spotlight series on our webpages and created a webinar series entitled: Community Voices.

In 2022/23 we welcomed a wide range of community organisations offering them a platform to share their inspirational work. We were delighted to host HealthBus,

The recordings are on the Centre for Seldom Heard Voices website under Community Activism: www.bournemouth.ac.uk/research/centres-institutes/centre-seldom-heard-voices

community researchers were supported by academics from BU PIER who are experts in designing such engagements with underserved groups using creative approaches.



Kathryn Loughnan Director of Partnerships, Research and Influence at Help & Care

Escapeline, Drop the mask, ICN (International Care Network), West Howe Community Enterprises, Bournemouth YMCA, BCP Poverty Truth Commission, and the South Dorset Research Group. The webinars were all interactive, engaging and inspiring, with some speakers choosing to prepare a short presentation and others opting for an In conversation with.... format before we opened up the session for discussion and Q&A with the audience. The webinars and the recordings continue to build connections and collaborations between BU researchers and community organisations, supporting those currently underserved by research to have an opportunity to influence and lead on research projects and research priorities.

# **PIER members: what PIER means to me**



"I love how diverse PIER has become over the years. It gives students a wide variety of life experiences they may encounter in their work." Sue Smith

"I never went to uni but I like to learn so this gives me a chance to see what going to uni is like and I help teach people which is another unfilled ambition. I love meeting new people and talking to them.

I like being challenged to get out of the house which is great for self-confidence.

I get to learn from other members and how the government and their charities help them." Karen Wye

"PIER gives me a voice to talk about my own lived experience. A chance to help students on various courses that I've assisted with in learning, how to communicate with people with disabilities. It also helps fill up my day, which in turn helps me with my own mental health.

I have helped out with social work, paramedic science, nursing, physiotherapy, and occupational therapy courses." Iain

"PIER - For me personally has challenged me intellectually and socially, taking me out of my comfort zone to speak via Teams, Zoom or in person on given subjects that I would have never thought possible. Over time PIER has given me confidence in my own ability and also a brief understanding of Research. I now realise that my voice is just as important as anyone else's, and to be heard and incorporated into research would give a better outcome overall. Over time I have increased my knowledge as well as co-facilitating a CPD Unit, proof-reading a document, a webinar along with many other things and I personally like being involved from the very beginning to the very end." Julie



"PIER means to me: Feeling important and valued. Over the 7 years, l have been involved in the nursing and paramedic side, both

as a patient, so that they have better understanding of how their support and work affects the patient in their mental and physical recovery. I have assisted researchers as a member of the public. This has involved in helping them seeing what effect their topic has in shaping their decisions to how they put this forward in a request for a grant.

This has given me growth in my confidence. Always treated with respect and knowing my voice is valued. It has also allowed me to meet very interesting staff and colleagues, which is very enjoyable and interesting.

Makes me happy too."

Sylvia Sere

# International involvement

Increasingly PIER are being invited to share experiences and learn from colleagues from other countries. This year we met with colleagues from Australia, USA, Canada, Ireland, Sweden, Israel and Norway to discuss and collaborate on public involvement in education and/or research. One example has been with colleagues in Norway.

### Western Norway University of Applied Sciences

Over the past few years, PIER have established a working relationship with the Western Norway University of Applied Sciences with BU PIER previously hosting visits from academics from the university and Mel visiting and sharing the PIER approach to colleagues in Norway. This expanded this year with Pete bringing together social work academics and PIER members from both universities.



"Since the fall of 2022, a group of Norwegian academics have kept in touch with Ros and Peter by email and digital meetings. BU has shared information about how they collaborate with members of the public regarding their Social Work program and how PIER

members are involved in teaching, assessment, and quality assurance. We have shared our articles about research circles as a methodology for participatory research. This led to Academic staff and public contributors meeting online to learn from each other. "

#### Mariann Iren Vigdal

PhD Candidate, Department of welfare and participation, Faculty of Health and Social Sciences, Western Norway University of Applied Sciences



"I shared that it was important for students to hear our stories face to face as virtually it can be difficult to read students especially if their cameras are turned off. Physical interaction is very important and more personal, and students get more out of the sessions

this way. Giving the students feedback and them giving us feedback works very well. Gives us and them validation of the session. Also is nice to hear that we are appreciated for what we do.

I did like that Norway gave their service users qualifications for their service."

Kathryn H BU PIER member



"It was friendly and we had a great time sharing our experiences. It was a long meeting but would have easily had longer to discuss things. Their English was very impressive too! I'd happily be involved with this type of activity again."

Mandy B BU PIER member



"The overall impression I recall of this session was how much the Norwegians' focus was on individuals impacted by drug and substance abuse compared with BU's broader involvement with service users living with a wider range of conditions and circumstances. BU's

approach on the whole is to direct lived experiences into learning programmes rather than directly assisting individual service users."

Nigel P BU PIER member



"It has been fascinating to meet and listen to how Mariann and her team have involved people with lived experience in their social work programme. We have been able to share experiences around research and teaching to gain different perspectives on how to improve student

experience. I hope we can continue to keep links with a view to developing possibilities for collaboration in the future."

#### **Ros Dray**

BU Senior Lecturer in Social Work



"It was interesting to see how the universities used PIER differently, with BU focusing on undergraduate education and Norway focusing on supporting those with addiction. I found hearing the PIER members thoughts on how sessions are delivered really useful in guiding me

to plan future PIER sessions within my teaching units. The meeting highlighted how PIER is very adaptable and can be used to support both patients and students."

#### Emil Siwadi

BU Senior Lecturer in Operating Department Practice

# Writing journal papers

In last year's report we shared examples of PIER members and BU academics co-authoring three journal papers on public involvement in physiotherapy education. With the aim of contributing to the growing evidence base for effective public involvement in health education, we expanded this in 2022-23 by collaborating with colleagues in Operating Department Practice (ODP) and Occupational Therapy (OT) to co-author papers with PIER members. Preetee (OT lecturer) and Julia (PIER member) reflect on this process.



"BU PIER has created a platform for sharing perspectives and valued experiences of service users within Occupational Therapy education. Curricular sessions that have been codesigned and co-delivered with PIER members within Occupational Therapy

programme are much valued by students.

With the support of Mel from PIER, I decided to reach a larger audience through writing a journal article explaining the importance of PIER partnership within Occupational Therapy education.

There is scarcity of published evidence within this domain of Occupational Therapy practice which triggered our motivation to write a reflection of our work in collaboration with a PIER member. Julia was equally keen to pen down her thoughts. We started working on our individual reflections about the session delivered. We are currently in process of compiling our work with an additional emphasis on 'importance of co-creation with PIER members and its inclusion in Occupational Therapy curriculum'. We aim to publish this work in a peer reviewed journal."

Preetee Gokhale

Lecturer in Occupational Therapy



"I have been a PIER member for the past seven to eight years, having retired from Nursing due to my Parkinson's. I find working with the Occupational Therapy students interesting, fulfilling and motivating, particularly in giving insight that they wouldn't ordinarily have, about what it's like living with a long-

term illness. Ultimately, it could make a difference in their future patients' lives and help them understand the role Occupational Therapy has in supporting patients like me.

The key thing I wanted to achieve was to share the message, that someone with Parkinson's can come out as a powerful, independent and strong person despite the challenges Parkinson's presents."

Julia PIER member



# **Involvement in education**

PIER continues to develop the range and content of sessions in undergraduate and post-graduate education and CPD (continuing professional development) courses. In the last academic year, we planned and delivered 159 sessions with 51 different PIER members, providing 1410 contact hours between people with lived experience, staff and students. Feedback from students consistently highlights the value of this involvement and its relevance to future practice.

Year on year we reflect on the work we do and adapt the input we provide, to ensure that it is up to date, is in line with NMC, HCPC and Social Work England standards for education and enhances students' learning.

As there are so many examples, we have chosen to shine the spotlight on two sessions over the last year: the first being one within the Independent & Supplementary prescribing CPD unit. Mandy and Deborah (PIER members) share their experiences of collaborating on this unit.

### Independent & Supplementary Prescribing CPD unit

#### Mandy's perspective



"We sit in groups and the students rotate round the groups so that they get a range of different experiences. Even though the students are already in practice they always feedback that they've learnt something new, and it reminds them to be patient centred.

I am impressed that the lecturer always introduces us and explains everything."

#### Deborah's perspective (PIER member)



"I thoroughly enjoy speaking to current health care professionals from a variety of backgrounds as they confidently interact us with us as they are specialists in their own fields. They are not afraid to ask questions and I think it's a unique insight for them to be able to speak to

carers and service users alike. I feel it also makes them stop and think freshly about their future patient interactions.

I get a sense of fulfilment interacting with the variety of health care professionals on a one-to-one level. Everyone gets a chance to speak and ask questions. And within each session the dynamics are always different, and it makes for interesting and worthwhile conversations that resonates with all involved. It's one of my favourite sessions, I always leave tired but happy."

### Matthew Hartwell's Perspective (Senior Lecturer)

"PIER involvement with the prescribing program is unique and offers the students, a deep and valuable insight into how patients feel and their experiences about being prescribed medication by non-medical prescriber. It is valuable in the respect that students cannot normally ask patients the questions they ask in this safe environment, although perhaps wanted to whilst in practice. This has now been included in our program for three years and is always superbly evaluated by our students."

### **Paramedic Science**

Our second example of involvement in Education is within Paramedic Science; a unit called Patient Assessment Fundamentals, involving 12 PIER members over a 3-day period.

### Stuart Hall's perspective (Academic)



"The students are tasked to review the patient's medical history and then complete a patient report form afterwards. They are 1st year students and will be asking fundamental medical and social questions only.

This communication exercise was all about giving our Level 4 (first year) students experience and exposure to communication and patient history gathering with real patients prior to them going out into their first practice placement. Overall, it went really well, and the students' feedback was really positive. They felt it was a valuable exercise, especially with the PIER members playing the role of the patient and being able to offer the student direct support and feedback."

### Deborah's perspective (PIER member)



"The 3 role plays went well considering it was their first time dealing with 'patients'. I was impressed by the standard of my students. I think this is a great part of their course work in preparation for their upcoming placement. It was very enjoyable and a very useful part of the course for them."

### Peggy's perspective (PIER member)



"I thought the whole event was good. Overall, the skills shown were good and the students seemed to appreciate the feedback. As a "patient" I felt included and listened to by the students, bearing in mind it was their first experience of history taking and they obviously

still have a lot to learn. The main skill I felt was lacking was being able to pick up clues from the answers to their questions and expand to gain more information.

I found it a positive experience and will be happy to take part again in the future."

# Involvement in professional practice

Our work to harness lived experience expertise at BU also has a positive influence on professional health and social care practice.

This year, PIER members were invited to take part in World Social Work Day on 22 March. In a time of huge challenges in the health and social care sector, the social work team chose to hold an event to share positive stories of social work. The event will provide a springboard to creating a regional repository of stories which participants will be invited to add to, and which can be shared with wider networks to promote social work and social care identity.

Carolyn and Peter (PIER members) and Ros Dray, Senior lecturer in social work, share their reflections on the project.



"This project was a work of collaboration which culminated in a video of PIER members and an event in March 2023 which I feel genuinely proud of. The project really reflects the passion and commitment PIER members have around enabling student learning. Working with

PIER members to put forward ideas, shaping this up into a plan and creating the video was a huge learning experience for all of us. Using digital stories and pictures to capture the experiences of positive encounters with social workers was both rich and emotive.

This project was also shared at a national social work conference in Glasgow and practitioners across the UK expressed interest in contributing. Watch this space!"

Ros Dray

Senior lecturer in social work



"I so enjoyed being part of the social work positive stories event to capture our lived experiences on video. It felt like an honour to represent PIER on an innovative project. So often in activities with students we share stories of poor practice, this time we were celebrating

successful interventions and practice and inspiring by highlighting excellence.

I felt nervous being filmed without any prior practice but being natural proved to be the most effective way. The exercise of choosing a picture that expressed our feeling about our stories was wonderful. I love pictures and colours and am a visual learner, so the exercise appealed to me. In the end I chose to describe 2 pictures as I couldn't put either down! Expressing our feelings was very powerful and viewers of the video have said it really helped them to listen to us explain our choices of pictures."

Carolyn L PIER member





"We were well prepared by Ros from the Social Work Department. She explained clearly the purpose, the intended audience and the process and we were encouraged to share our thoughts on the process.

The day of the filming was kept low key and relaxed. It was a matter of talking to camera. Some preparation proved helpful as my example was not particularly recent and helped me to focus on the social work intervention and outcomes.

At the end of the video, we were asked to choose a picture which best reflected our feelings about the positive story. I chose a picture with multi coloured balloons as the social worker's care, non-judgementalism and optimism had given me hope that life could be fun again even though my circumstances hadn't changed.

I hope that these stories will encourage students in a difficult and challenging role."

Peter L PIER member

You can view the positive stories film here: www.youtube.com/ watch?v=c2wd-8DFtdA

# **Educating researchers**

For two years now PIER has delivered a co-designed master's level CPD (Continuing Professional Development) unit to researchers. In 2022-23 we built on this by co-producing and co-delivering public involvement in research workshops, coaching, and masterclasses across the region. The aim of all these sessions is to support researchers to develop more inclusive ways for people to be involved so research can be informed by people who are most affected by it.

"I never thought that my voice would be heard by top level consultant in the hospital and that I could show them a different way of involving members of the public in research and service development. Things are really changing and developing; it's no longer about the old systemled ways. I helped make changes for a better and more inclusive future."

Christine Bondsfield PIER member

PIER was also funded to co-produce and co-deliver a bespoke training and coaching programme for NIHR Clinical Research Network (CRN) Wessex, to build capacity in the research workforce to engage marginalised groups and communities currently under-served by health and social care research. 44 researchers from cross the Wessex region (Hampshire, Isle of Wight, Dorset and South Wiltshire) booked on to the one-day training course, with 10 being offered additional 2:1 coaching with either Mel Hughes (Academic lead) and Julie Cherry (PIER member) or with Kate Jupp (PIER officer) and Rachel Jury (PIER member). Learners spoke very positively about what they had learned."

### **Quotes from learners:**

"The coaching sessions were brilliant and sessions have been really encouraging very appreciated." and I would highly recommend to others."

"The combination of the training and coaching has been timely for my role."

"It was informative and interesting and well worthwhile having the coaching."

"I have really valued the programme, particularly the coaching sessions, as they have helped me identify ways to expand and enhance engagement with those who are truly underserved. They have helped to validate my current knowledge and explore other methods to reach out to individuals and communities. The

### **Reflections from Julie Cherry PIER member,** who was part of the coaching team

"I enjoyed coaching individuals and seeing the growth before your eyes. I would honestly say that before this I asked myself "what can I coach professional and/or academics on research?" and "what do I bring to the table?" well, I bring my knowledge of the real world, I was able to point them to different people and sometimes say why they are failing to engage. Everyone's voice does matter and that is what I got out of this, as well as pride."

"The coaching has influenced the way I have approached important parts of my work. It was pitched at just the right level!"

"I wasn't originally booked on the coaching sessions, but when a couple of spots became free, I took one of them, and I'm so glad I did!"

"...I didn't know if they would be relevant/ suitable for me and wasn't sure what to expect. But they were so, so useful and I am so glad I managed to get a spot."

# **Collaborating on research bids**

The biggest area of growth for the PIER partnership this year has been our role to involve people with lived experience in applications for funding (bids) for BU research projects. This growth has been possible due to funding for Kate's PIER officer role to support involvement in research and Mel's secondment for 2.5 days a week to develop this work. As the year in numbers show, this led to PIER supporting people with lived experience to be actively involved in shaping and designing 53 applications and projects between September 2022 and August 2023 (a increase from 10 the year before). Two examples are shared here to illustrate the different ways that PIER have been involved.

The first example is an application to the Medical Research Council led by Dr Ala Yankouskaya Senior Lecturer in Psychology from the Faculty of Science and Technology at BU to fund a research project to evaluate the effectiveness of cold-water immersion as a treatment for depression.

### Cold-water immersion as a treatment for depression project

#### Sarah Beasley New PIER member



"My first experience of PIER was through a zoom session to seek service user feedback on a research project into cold water therapy. I had registered my interest to be involved on the VOICE website. VOICE provide information on opportunities for service users and the

general public to be involved with current research projects. The session was facilitated by Kate (PIER Officer) and I was impressed how she facilitated the session to stimulate an interactive, engaging discussion between service users and the researchers. The research team provided information on their proposed study then sought feedback from group members on their thoughts surrounding cold water therapy. The session covered how the proposed research could be put into practice including recruitment to the study, provision of pre-study information, the implementation of the intervention and follow-up sessions. Through a carefully planned agenda, Kate ensured that everyone felt able to contribute in a supportive environment and the researchers appeared genuinely grateful for our contributions.

Following this session, I sought further information on PIER and have now been enrolled as a PIER member since September. I am excited to have the opportunity to be involved in both education of students and research projects. PIER allows me to use skills gained during my career as a physiotherapist and postgraduate MSc studies alongside my life experience as a service user, to influence research projects as well as keeping up to date with educational opportunities for health care professionals."



### Dr Ala Yankouskaya Senior Lecturer in Psychology Faculty of Science and Technology

"The workshop exceeded our expectations. Participants in the workshop actively engaged in discussions about aspects of experimental design, social acceptability, relevance, potential advantages, and limitations of our proposed study. Moreover, we received comprehensive suggestions on recruitment procedures to engage potential volunteers.

During the workshop, Kate, from PIER, prompted several critical questions regarding the benefits and challenges of developing cold water immersion as a therapeutic option to alleviate depressive symptoms. These outcomes have provided invaluable insights for our forthcoming MRC application.

The success of this workshop can largely be attributed to the feedback process, where Kate's pivotal role was invaluable. For instance, she adeptly coordinated the flow of communication during the workshop, while also allowing us to take the lead in discussions. This approach created a very positive and trusting environment where patients and researchers worked as a team. Moreover, this collaborative approach enabled us to generate numerous innovative ideas for project development. In addition, as a researcher with no prior experience in PPI, working alongside Kate was a very positive experience for me."

### Dr Heather Massey Senior Lecturer in Sport, Health and Exercise Science and member of the Extreme Environments Laboratory and Clinical, Health and Rehabilitation Research Team (CHaRT) at the University of Portsmouth.

"The PPI session was fantastic, not only did we get a real insight into what participants thought about research in general, but more specifically how we can design research to appeal to people and help provide information that could reduce barriers to participation. It was a real eye-opener and a fun session to be involved with."



#### Nutrition in care homes project

Our second example on involvement in a research bid was for an NIHR (National Institute for Health and Care Research) funding bid regarding nutrition in care homes. PIER were asked to harness lived experience expertise to ensure that the study was relevant to those it was designed to help.

#### Nigel Herring, Regional Manager, Classic Care Homes (Devon) Ltd



"I oversee the management of two residential care homes and a domiciliary home care service in Devon. We were keen to take part in the research project that is looking at oral nutrition supplementation in care homes. I organised for residents, staff,

and relatives from both homes to attend meetings with Kate Jupp and have informal conversations to discuss what is important to them about the food and drinks in their care home setting. The project gained views from residents of what food they enjoy, what they like, and what they understand and feel about the importance of eating and drinking well for their own health and wellbeing. I hope that by continuing to collaborate we can be part of a project that will help find tasty, healthy and natural ways to support nutrition and hydration that can be enjoyed by the residents we support especially when they have difficulty eating, drinking, swallowing, have a poor appetite, and are at the end of life. I will be a stake-holder co-applicant on the project if the project application is successful and we continue to work in partnership with the research team."

### Professor Jane Murphy, Deputy Dean, Faculty of Health and Social Sciences, Bournemouth University and Mary Hickson, Professor of Dietetics, University of Plymouth

"Working together with BU PIER for our NIHR research proposal was invaluable. PIER provided insights into the current approaches to support the delivery of nutritional care for older people living in care homes. Taking a whole care home approach was key; engaging with all those involved including managers, care home staff, residents, and family carers. Thank you, Kate and team!"



# **Collaborating on research projects**

Once a funding application is successful and a research study is underway, PIER remain involved to ensure that lived experience expertise informs all stages of the research project and that public contributors including PIER members, are supported before, during and after all activities.

One example of this has been a qualitative research study to gain insight into the impact of the cost-of-living crisis on carers which involved PIER officers Kate and Pete.

### Carers and the impact of the cost-of-living crisis

On 5th June, the first day of carers week 2023, six carers from Dorset met for the first time and shared experiences of the effect of the cost-of-living crisis on their caring role. During the previous two weeks, each carer had taken photographs to capture the impact the cost-of living crisis was having on them, and their caring role. Using the qualitative research method of photovoice and working in partnership with the carers, this BU project in collaboration with PIER will use these experiences of caring during the cost-of-living crisis to improve knowledge, call for change and to identify future research priorities. At the workshop, facilitated by Professor Lee-Ann Fenge (Professor of Social Care) and Dr Kate Jupp (PIER Officer), and supported by co-researchers Pete Atkins (PIER Officer) and Angela Skeparovska (student research assistant) each carer shared the story and meaning behind each of their chosen photographs; the photographs being the catalyst for the stories that emerged.

https://ncpqsw.com/research/the-impact-of-the-cost-of-living-crisis-on-carers

#### Lesley Barlow (Carer and New PIER member)



"We were asked to provide 5 photos showing the impact of the crisis on our lives. It was a lifeline that I did not know I needed as each person in the room shared their story through a series of photos, each story and photo was very emotional which brought tears, laughter

and anger at the injustice of the systems we were faced with but more than that as a group we listened and were listened to and felt supported.

The impact of being with a group of people going through very different individual situations was enormous but there was a thread, just being able to say out loud all the things you keep inside, the love for the individuals we care for, the recognition that we need to take care of ourselves in order to cope, that there are people who will listen and there are signposts for help and support.

The photos were so impactful that I found myself thinking constantly of the members of the group wondering how they were getting on.

The second session saw us meeting like we were old friends as we reviewed the photos and changes that had taken place within the group. A discussion was held on how we could take things forward so that a Carer's voice could be heard. Each Carer's situation is unique, one social services plan size does not fit all.

Our voices will be heard as the next stage is recording our stories. We are living longer and whilst you might not be a carer now, you could be in the future. What would you want for the person you may have to take care of?"

#### Ekaterina Werenowska (Carer and New PIER member)

"While each person had a unique experience, there were common themes which resonated. Participation gave me the opportunity to reflect on what the future might hold. The opportunity to contemplate the responsibility I have accepted at a deeper level, and to critically assess my skills and experience in preparation for what lies ahead has been invaluable."

#### Jason Pink (Carer)

"Before getting involved in this, it felt like I was alone in a dark place. However, hearing shared experiences and realizing that others are in the same situation lightened the load for me. It made me understand that I'm not alone in this journey, and it motivated me to take action and do more research."

#### Kim Sommons (Carer and New PIER member)

"I share the sentiment of many in the group that the experience was truly powerful."

#### Aidan Foy (Carer and New PIER member)

"This experience has motivated me to become more involved in workshops and other activities. I genuinely found it to be a great experience, and I'm excited about taking it further. Discussing these issues is essential for us, and it also has a significant impact on the organizations involved."



#### Moonmoon Rahman (Carer and new PIER member)

"Joining this group has given me a platform to speak openly and share my experiences without feeling ashamed or judged. Here, I can discuss anything I want, and I'm truly grateful for that opportunity."

As a co-researcher on this project, Pete was able to draw on his well-established relationships with people across the local and national carers community.

#### Pete Atkins (PIER officer and co-researcher)

"I initially made contact with BCP CRISP (Carers Resource Information and Support Programme) to identify carers for this research project. I also linked up with Carers UK with both their Head of Carer Support and Policy and Public Affairs Manager to link in with both Carers Rights Day and the Carer Poverty Coalition and we will continue to develop these connections."

### Angela Skeparovska (undergraduate student research assistant and co-researcher)

"This research has been meaningful to me. Before my involvement, I had limited exposure to carers and their struggles. However, this research has revealed that carers grasp on far more profound challenges than I thought possible. They often work long hours with little compensation, lack adequate support systems, and face numerous administrative barriers. Having the opportunity to see how much carers are undervalued I feel that it's time for us to recognise and talk more about the important role carers take on in their daily lives."



# **Community-led research**

We have been involved in several funded projects this year using the BU PIER Community **Researcher Model where PIER provide support** and mentoring to people with lived experience and community partners to conduct research as community researchers. We are finding it to be a hugely effective approach to involving people who do not typically engage in research and whose voices are seldom heard and as a way of supporting community partners to engage in research based on priorities they have identified. We have invited some of those involved to share their experiences.

### Whatever it takes project

Katie Munday (community researcher), Whatever it Takes project: Involving people in understanding cancer services for Disabled and/ or neurodivergent people

"I really enjoyed this project and got so much out of it, as I hope the attendees did. It was amazing to reflect on my own experiences during workshops, which helped others to open up about their own experiences. Accessibility was a really important element of this work for me, as an Autistic and chronically ill person I have had people try to recruit me without giving a second thought to accessibility. I wanted to ensure that attendees felt validated and championed in their identities, experiences, and knowledge.

Personally, to be in a room full of other Disabled people was amazing: the communication was easier, and conversation flowed better, there was no need to hide any parts of us. It doesn't seem to matter what Disabled space I go into, or whether I share the same bodymind as those in the group, I always feel welcome and I always feel at home.

At the beginning of the project, I felt slightly deflated with delays as I knew how important and empowering this project would be. However, I understand how neurodivergent and Disabled people can lack the energy and time to be involved in grassroots research. We had to meet the individuals and the groups where they were, not where we expected them to be.

The attendees have been amazing with what they have shared with us, and I'm truly honoured by their time and the stories they shared with me."

Rosie Tansley (community researcher), Whatever it Takes project: Involving people in understanding cancer services for Disabled and/ or neurodivergent people



"I have thoroughly enjoyed being a part of this project and am thankful to have been given the opportunity to be involved with such meaningful work. As an autistic and chronically ill individual, I felt welcomed and included by the research team who, through their regular

check ins and meetings were able to provide a space where I felt supported and able to share when I was feeling a bit overwhelmed and needed some additional guidance.

Being a community researcher involved in the workshops was a valuable and affirming experience for myself, and I hope that this was something also shared by our attendees. The process of connecting more deeply with attendees through shared experiences when discussing topics that can be distressing and sensitive in nature was cathartic for everyone involved on many occasions. Through our shared experiences, I was also made to feel less alone, and when reading the feedback from the workshops, it was really nice to hear that attendees felt that we were able to create an environment where they felt comfortable to openly share their thoughts and experiences with us too.

There were times during the project where I felt a bit uncertain about where it was heading due to some ambiguity at the start, however, there were always opportunities to talk this through when needed.

Overall, this has been an amazing project to have been part of and I am so excited to see how it develops further."

### Stevie Corbin-Clarke (BU research assistant)

"Working with PIER has meant being a part of and helping to develop safe and enabling research environments, and approaches which are respectful and empowering for all. This pilot project for the BU PIER Community Researcher Model, has only served to solidify my confidence in the power of developing strong relationships with community researchers and partner organisations, in which you all learn and grow together. These relationships encourage and allow for the development of unique and innovative ways of carrying out research, through which we can capture and amplify the voices of those who are seldom heard. I have had the privilege of witnessing a huge growth in confidence and skills of the entire team throughout this project. It has been incredible to see changes already being made in practice as a result of everybody's hard work."

For further information: Involving People in understanding cancer services for disabled and/or neurodivergent people and www.helpandcare.org.uk



### Hidden Hunger project

### Rev Sandra Prudom (Christchurch Community Partnership Chief Executive Officer)



"I am the CEO of the Christchurch built a relationship with the attendees which they greatly Community Partnership a small valued. The research and subsequent report have been independent charity working to address immensely helpful to us in informing future projects. We social isolation in the Christchurch are starting a new 'Sunday Roast' project to bring our more area. We were excited to work with BCP isolated residents together on a monthly basis for a Sunday Council's Access to Food Partnership and roast after reading the comments about how difficult many the BU PIER Partnership on a project of our clients find the weekends. We have also circulated around Hidden Hunger. We discovered through our the PIER report to other organisations we work with. I hope response to the Covid pandemic, that many of our residents our involvement with BU PIER has been helpful in shaping struggle with food insecurity as well as social isolation, future research projects by supporting involvement of and this is something we felt we needed to address by folk with lived experience of the issues. We are very much supporting more Lunch Clubs with our Christchurch Angels hoping to work with PIER on another project around access and Transport services. We worked closely with Dr Kate to health care in the near future!" Jupp who visited the Lunch Club on several occasions and

You can read the report here: https://acrobat.adobe.com/link/track?uri=urn%3Aaaid%3Ascds%3AUS%3Afcdb0868-1640-32fabdc9-a462c6fabead

### Our plans for next year 2023-2024



All of our work in PIER is guided by our five-year PIER strategy but this is a working document which is growing and evolving as we are. The PIER strategy 2025 outlines the BU PIER Partnership's five-year plan for ensuring that the expertise of people with lived experience (including patients, potential patients, carers and people who use or represent people who use health and social care services) underpins and informs education, research and professional practice at BU. When we co-designed the strategy back in 2020, I don't think any of us guite anticipated just how successfully we would achieve this goal. The examples throughout this report demonstrate a huge array of work, projects, activities and collaborations that show how lived experience expertise underpins and informs education, research and practice at BU. What is also evident is the wider impact. Individuals have reported feeling valued, heard, welcomed, included, and important. Community partners and colleagues describe the impact of PIER involvement as exceeding expectations, being enlightening, an eye-opener, a partnership, informative, valuable and helpful. We have a remit in PIER to develop a culture for meaningful public involvement in education and research at BU and our collaborations are extending this reach

even wider by creating and sharing a platform to amplify the voices of people with lived experience and flipping the power so people have control. Our main goal as we head into 2023-24 is to build on the success of these relationships, partnerships and collaborations to continue to inform and support the development of inclusive practises and methods where everyone in society has the opportunity to shape and inform research, education and professional practice that most affects them. The overarching goal is to harness lived experience expertise to address health, social and economic inequalities which improve outcomes for all.

As always, having such bold goals and plans are only possible due to the breadth and range of expertise across our partnership. We are excited and ready to see what the coming year brings.

**Professor Mel Hughes,** Academic Lead for the PIER partnership

Angela Paget, Pete Atkins and Kate Jupp, PIER officers

# A final word from our members

"I thought the session was really good and worked so well, it was very user led and the feedback to students was more me. I felt very valued." "Personally, I got a lot out of helping them and wish them well for the work in the future and I would love to do more like this in the future."

Keith Hunt, involved in MA Social Work year one: Roleplay, November 2021

"I found this morning a positive time, the students were attentive and working with Sarah was a pleasure, our narratives complemented each other, and we worked well in partnership."

Joy Ford, involved in BSc Paramedic Science year one: Mental Health and Addiction, May 2022

"They are some of the most engaged students that I have come across in my 5 years being involved with PIER. I think we all enjoyed being involved in this session."

Deborah Curtis, involved in BSc Physiotherapy year one: Chronic Pain, June 2022

"Overall, the students were inquisitive and fun to talk to. Splitting into two groups was ideal and made it easier to engage with the students."

Julia Gracey, involved in BSc Occupational Therapy year one: Stroke and Parkinson's, March 2022

"My role within BU PIER as always has been very important to me, not only with the interaction with students but yourselves in the wonderful way you support members. It has enabled me in my own recovery as well as some members of my own family."

Iain Sutherland, involved in BA Social Work year one: Communication Challenges, September 2021

"I found the experience to be very good, I was a bit worried at first as I was not sure how to relay my thoughts and experience, I think I shocked a few with some of my comments."

Karen Wright, involved in BSc Operating Department Practice year one: Cancer and MS, March 2022

"There was lots of engagement with the students. Lots of different people asked very good questions. The students were listening well and were interested in my experiences."

PIER member, involved in Clinical Pharmacology & Medicines Management

# **Contact us**

Professor Mel Hughes Mhughes@bournemouth.ac.uk

Angela Paget Angela Paget@bournemouth.ac.uk 01202 962022/07912 785009

### **Peter Atkins**



Dr Kate Jupp kejupp@bournemouth.ac.uk



# www.bournemouth.ac.uk/pier