



**QUEEN'S
UNIVERSITY
BELFAST**

PATIENT AND CARER
EDUCATION
PARTNERSHIP

Annual Report

*Patient and Carer
Education Partnership
Forum (PCEP) Annual
Report 2022 - 2023*

September 2022 to August 2023

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Message from Professor Karen McCutcheon – Deputy Head of School



As a School of Nursing and Midwifery it is imperative that the patient remains central in all that we strive to do within education. The role that the Patient and Carers in Education Partnership (PCEP) forum play in the life of the School ensures that this central premise of our professions is always present.

The PCEP forum is a diverse group whereby all members are considered to be highly knowledgeable and motivated individuals. PCEP members are eager to contribute to make tangible impacts and change in the education of our nursing and midwifery students. The ultimate force behind this forum is the desire from all those involved to help create a healthcare system that is caring, compassionate and safe for both patients and healthcare professionals. The work of the PCEP forum challenges us as healthcare professionals and healthcare students to really consider and engage in true person-centered care.

The success of PCEP is not the work of any one individual, but is a collective collaboration where everyone is considered equal with a voice and a contribution that is considered significant. This foundation of inclusion and respect is one of the most important principles which makes this forum so successful.

QUB School of Nursing and Midwifery are extremely proud of the PCEP forum and all that it has achieved and continues to achieve. We are delighted that these achievements are now recognised not just within the School but the wider faculty and University Personal and Public Involvement and indeed the health and social care sector across NI.

Thank you!

Professor Karen McCutcheon, Deputy Head of School

ABOUT US: OUR AIM, VALUES AND APPROACH



Our Aim – to continue working in partnership within the school to educate and promote positive outcomes for the future nurse, future midwife.



Our Shared Value – the PCEP Forum promotes the participation in effective and meaningful coproduction activities between patients, carers and staff within the school.



Our Approach – To involve people with life experiences as consultants, reviewers, facilitators, interviewers and assessors due to the expertise they bring and the experiences they share.



Rosie Peters
Co- chair of PCEP
Forum

I have been co-chair of PCEP since September 2022, working to promote patient

and carer involvement in the School of Nursing and Midwifery at Queen’s University Belfast.

I registered as a nurse in 2004 and practiced in an acute medical ward in the Belfast City Hospital. My passion to deliver excellence in patient care, led to my interest in teaching. Throughout my 14-year teaching career, I have developed my own teaching style, appreciating individual learning styles, and embedding strategies to optimise the learning experience of my students.

I have discovered the value of bringing patients and carers into the classroom to share their experiences with students. This method of teaching bridges the theory-practice gap, putting a face to the condition and a person to the emotion, encouraging person and family centred care.

I am privileged to be part of such an amazing team and feel that their contribution to our teaching enables excellence in the development of our future nurses and future midwives. We work together to plan, deliver, and evaluate all courses delivered in the School. This report will outline the contribution PCEP make to all areas of school business. Members of the PCEP forum sit on all committees within the school ensuring public opinion is heard and valued. I believe that we are meeting the school’s 2030 plan objectives to lead in patient and public involvement and look forward to sharing best practice with external stakeholders.



Mary Duffin
Co- chair of PCEP
Forum

Welcome to the first PCEP Report

Firstly, I want to introduce myself, my name is Mary Duffin and I care for my daughter who has a rare genetic neurological disorder called Aicardi Syndrome. I have always been passionate about user/carers involvement.

I have been involved with the School of Nursing and Midwifery for over ten years now and I am delighted to be Co-Chair of PCEP.

I am committed to making sure that service users and carers’ involvement is fully embedded in all aspects of the school. I am proud of what has already been achieved in the PCEP Forum in the way we all work together and make an impact for our future nurses and midwives.



Gillian Higgins
Co-ordinator of
PCEP Forum

I have been a clerical officer in the school for over twenty years and have been involved with the PCEP Forum since the beginning which spans over 10 years. The Forum has developed greatly over the last four years by ensuring that service user and carer involvement is embedded in all aspects of the school. The forum has nearly doubled in size, and we now have around 38 members which includes service users/carers, staff and students. Most recently we have developed a steering committee, our own website page, created an induction pack and MS Teams forms to manage involvement and feedback. Having been a carer myself I am very passionate about the service user and carer voice being heard.

PATIENT AND CARER EDUCATION PARTNERSHIP (PCEP) BUSINESS

Steering Committee

The Steering Committee is made up of 14 forum and staff members and the purpose of this committee is to oversee PCEP business to ensure the whole forum is running smoothly and embedded fully within the School. This committee meets around 8 times a year depending on business needs. All work that is undertaken by this committee is shared with all members of the PCEP Forum.

Full Forum Meetings

The forum consists of around 38 patients and carers, staff members and students. The Forum was established around 10 years ago and continues to go from strength to strength with PCEP members being involved in all aspects of School business.

The forum meets quarterly in September, December, March and June each year and it follows a blended meeting approach of either attending in person or online.

PCEP Business

Support for members

- ✚ Patients and Carers who would like to join the PCEP group are invited to meet with the Co-Chairs and Co-ordinator to learn more about the Forum and what their involvement entails.
- ✚ All members receive a Letter of Engagement and Induction pack.
- ✚ New members are introduced to the members of the PCEP forum at the next forum meeting.
- ✚ The PCEP provides a staff champion to each member of the forum to help understand School business and build relationships.
- ✚ The PCEP provide Equality, Diversity, and Inclusion training to all members.
- ✚ The PCEP provides support to all members involved in School business.
- ✚ The PCEP collect feedback from Staff, Student and PCEP members on any involvement of a PCEP member within the School.

Involvement in Education



I have had the privilege of being involved with this group from the beginning and am proud to note this this is an extremely active group contributing to all aspects in the School of Nursing & Midwifery at Queen's University, Belfast. It was 2013 there was recognition in the School of the importance of contributions from 'service users' and 'carers. Up until then the input from these 'experts' was inclined to be ad hoc.

This now dynamic group who work in the School draw on their life experiences as they contribute to nursing and midwifery education at all levels. Members are involved in teaching and learning, student recruitment, curriculum planning and development, and all committee membership.

The new name, Patient Carers in Education partnership (PCEP) was launched in November 2021 along with the website. The diversity of the group felt this name captured best all that they are involved in.

It has been an honour to have been allowed to serve with this group who are an integral part of the team at the school of nursing and midwifery. The voice of patients and carers has inspired my own personal and educational journey, contributing to the experience of our nursing and midwifery students as they learn from the experts by experience.

The group has already received recognition by the Nursing and Midwifery Council, the University and recent external awards, however the most important accolade is the recognition by our students of the humbling insight they receive from the group as our students strive to become the kind, caring, knowledgeable, competent practitioners.

I wish the PCEP group well as they grow from strength to strength.

Best wishes

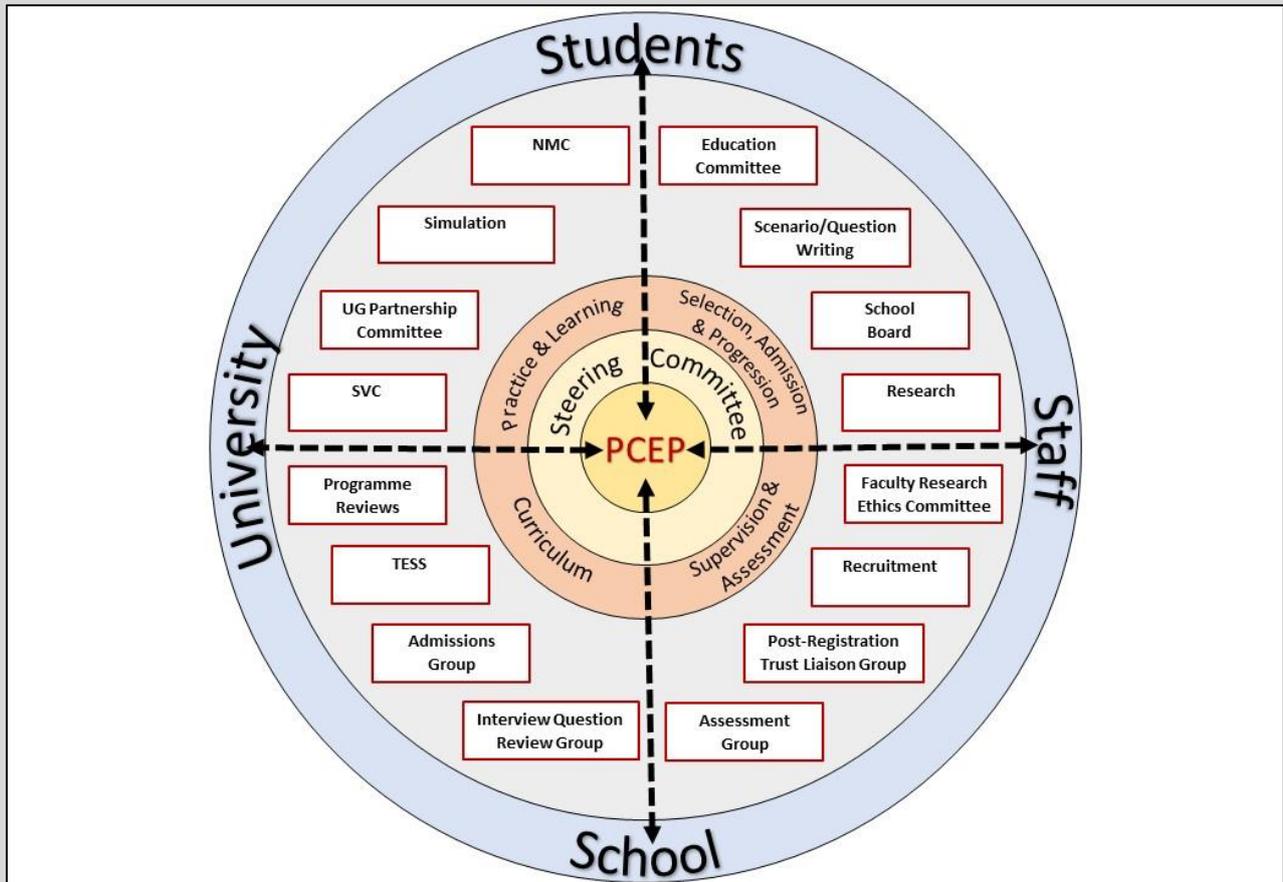
Susan Carlisle (Director of Education 2021-2023)



PCEP ENGAGEMENT

PECP Involvement- stakeholders chart

This chart symbolises the extent to which the Forum are involved with the co-production of all Nursing and Midwifery education programmes at Queen’s University Belfast. It demonstrates the level of involvement the group have with each process of student engagement and programme development. Student and Staff quote is included below:



“PCEP are involved in all aspects of the School. Students benefit immensely from the knowledge and understanding of the group members and their contributions enhances the students experience”

“The lecture from the Patient and Carer Forum member was extremely helpful and will benefit my future practice remembering to always listen actively and be honest always”

Individual PCEP members

Our forum has continually evolved in the last 10 years and continues to do so with patients and/or carers of patients within health and social care in Northern Ireland. We are also widely connected with other organisations and networks across NI and contribute these valuable experiences to the School of Nursing and Midwifery (SONM), QUB.

Being involved in the PCEP forum, we as members feel heard and appreciated as individuals with our own service user experiences. Each member contributes their own wealth of expertise that is hugely supported by the School of Nursing and Midwifery and invaluable to the teaching which is carried out in a collaborative approach.

The University has also recognised members of the forum for their commitment and passion to teaching as Honorary Lecturers. We love that we are at the heart of the School of Nursing and Midwifery and involved in all aspects from teaching, committee membership, student recruitment, curriculum planning and development along with assessments for example OSCEs. We also work collaboratively with other schools and public bodies.

To contribute to national Carers week, we delivered a week of lunchtime online discussions which can be now accessed through the universities YouTube channel, shining the light on Carers. Each day, discussions were led by the forum with very open conversations around recognising and supporting carers in the community. We feel that this is so important to give focus to themes and this really helps to bring life to the textbook for students.

We are all so passionate in the work we are involved in and due to our life experiences, we are very resilient individuals. Together we are really driven to make a difference in the teachings. The feeling of being valued for our time and efforts is exceptionally rewarding when we get such positive feedback from students and lecturers.

Our strength though ultimately is our partnership working within the school as
“We are better together”!

Written by Maria Somerville and Imelda Smyth





Quote from PCEP Member Maria Somerville



I have been a member of the PCEP Forum for 10 years.

I am the carer for my severely disabled son who has complex health needs. I use my experience and expertise of caring for him for the past 27 years within the SONM. I know from student and lecture feedback that my input enhances student learning and brings meaning into the classroom. I strive to bring theory to life for the students. I have been involved not only in teaching but in every aspect of the SONM.

I know I am a valued member of the team within the school as evidenced by being given the position of Honorary Lectureship.

Like all the members of the PCEP our greatest strength is working in partnership together with the professionals in the school to prepare our student nurses to practice to the highest standard. We want to achieve the best outcomes for our student nurses and ultimately this will enhance patient care in Northern Ireland

Quote from PCEP Member Imelda Smyth



I love the blended approach of our forum which allows for inclusivity wherever you are in Northern Ireland. For me, I believe that the future nurses and midwives need to see through the eyes of patients and caring with true compassion. By sharing my experiences and bringing insight to the voice of a mother, I hope to make a difference in the future maternity care in NI.



Raising our Profile

Honorary Lecturers

The PCEP Forum are delighted to have four Honorary Lecturers appointed within the School of Nursing and Midwifery: -



Mrs. Mary Duffin, Co-Chair of PCEP Forum



Mrs. Maria Somerville, Forum Member



Dr Scott Peddie, Forum Member



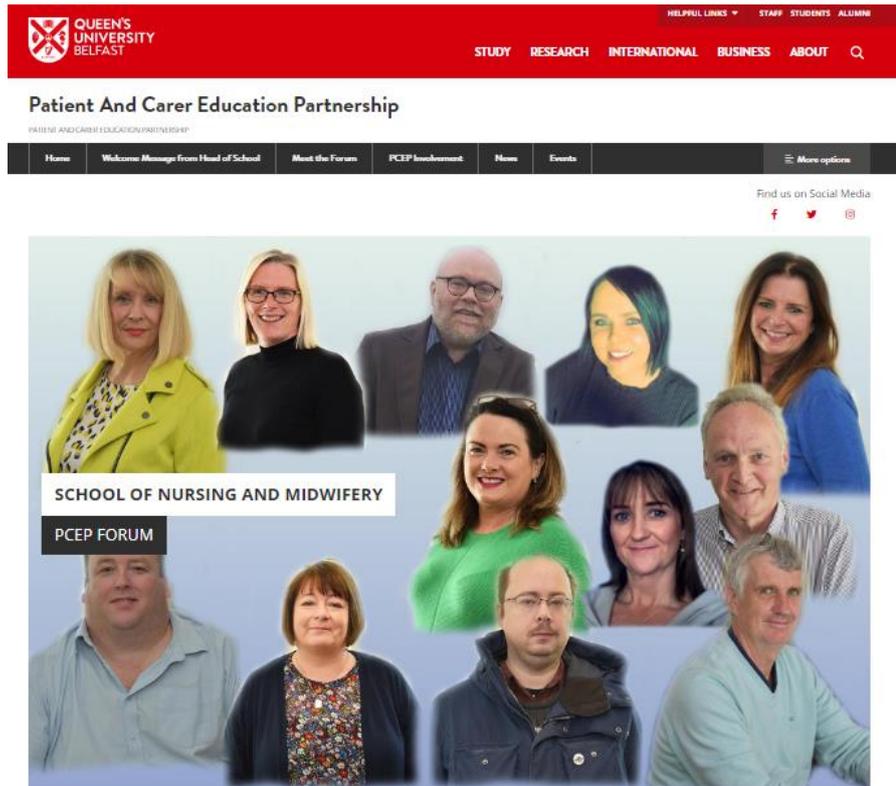
Mr. William Johnston, Forum Member

The First Graduation for QUB School of Nursing and Midwifery Graduate Entry Masters Professional Nursing (GEMS) took place on Thursday 13th October 2022 in the Whitla Hall. This led to three of our then appointed Honorary Lecturers in the Academic Procession at Graduation.



Patient and Carer Education Partnership Website

In 2022 we developed and launched our own PCEP website. This is an independent site of the School of Nursing and Midwifery and Queen's University Belfast, and it is managed and updated by the PCEP Co-Ordinator. The launch of the website is something that the Forum is extremely proud of, and we are working hard to continually develop the website, adding more depth and continuing to showcase the excellent work of the forum.



Carers Week sessions are available to view on the PCEP Website, these have all been uploaded to the School's YouTube channel and have proved to be an excellent training resource. We are currently building a resource section on the website to share these resources and demonstrate the importance of working in partnership.

The link to the website is <https://www.qub.ac.uk/sites/PatientandCarerEducationPartnership/>

Collaboration within our School and Queen's University Belfast

GEMS (Graduate Entry Masters) Programme



The PCEP group have been integral to the coproduction of nursing and midwifery education across the School. Their input into the coproduction of the pre-registration programmes was commended by the Nursing and Midwifery Council (NMC) at the joint validation event between Queen's University and the NMC. Within this process, members of the PCEP also supported the codesign of the Graduate Entry Masters (GEMS) in Professional Nursing, the first two year degree for graduates leading to registration as a nurse.

PCEP members continue to play a key role in recruiting and supporting students across GEMS, a flagship programme for the School. For example, PCEP members assess and rank portfolios, then support the development of interview questions prior to interviewing students as part of a tripartite team – this involves working with practice partners and academics to ensure the service user and care voice is represented as we recruit students with the correct values to be a nurse.

A key feature of the coproduced curriculum that PCEP members influenced was the focus on caring communication. This included an assessed role play to support students in developing these core skills. Members of the PCEP group now work with academics to provide feedback to students on the development of these essential skills in class.

PCEP members also support the development of partnership working for GEMs students in their final year as they support students in developing case studies for multidisciplinary team meetings incorporating the service user/ carer voice.

A core value in service user/ carer representation in nursing curricula is the power of the lived experience often recounted through storytelling. Whilst this remains in place across all our curricula, we have used the opportunity on the GEMS team to incorporate this valuable expertise of the PCEP group into assessment and supporting interactive learning activities.

Professor Christine Brown Wilson

GEMS Co-ordinator



Personal and Public Involvement (PPI) Network, QUB

Two members of the PCEP forum, Maria Sommerville and Mary Duffin, are also members of the PPI network at QUB.

The PPI Network at QUB are a community of best practice, working together to:

- ✚ Increase visibility and awareness of PPI being undertaken across the University, working in partnership with patients, carers, advocacy groups and those with lived experience.
- ✚ Signpost researchers and PPI contributors to the dedicated website, ppihub.org, which contains in-depth information about the Network.
- ✚ Expand the Network to ensure that all QUB PPI is represented and documented.
- ✚ Gather and collate PPI contributor and researcher perspectives and input e.g., to allow understanding of what training and support needs exist.
- ✚ Champion the work and initiatives of the QUB PPI Network across the University and our wider PPI Networks e.g., PPI Ignite Network in Ireland.

The PCEP forum has been working alongside Dr Maelíosa McCrudden who is the lead co-ordinator for the PPI Network at QUB.

School of Pharmacy, QUB

The School of Pharmacy contacted the PCEP forum for advice and guidance on how to set up their own service user and carer forum within their School. They have involved one of our forum members in a piece of work which involved writing a scenario for their upcoming Objective Structured Clinical Examinations (OSCE). This led to numerous joint meetings with Pharmacy colleagues and the PCEP Steering Committee where we shared our Induction Pack, Involvement Chart, Letter of Engagement and MS Forms. Members of the PCEP Steering Committee were invited to attend meetings independently with the School of Pharmacy, to start the initial setup process, these meetings are ongoing.

Collaboration with Community Partners



Bournemouth University

The PCEP Forum has been working collaboratively alongside Bournemouth University since the beginning of 2022 to share best practice and ideas on service user involvement. We have been working closely with Dr Mel Hughes, a Professor in social work and Academic Lead for the PIER (Public Involvement in Education and Research) partnership and Angela Paget and Peter Atkins who are PIER Officers at Bournemouth University. We have discussed the current involvement each University is offering, and we had great support from Bournemouth at our online Carers Week event in June 2023. Our Colleagues from Bournemouth provided information and support around the development of our PCEP Induction pack, this was very much appreciated and highlighted the importance of Co-Production and working together to share best practice. We will continue to collaborate and share good working practices around service users and carer involvement with Bournemouth, and we plan to arrange to meet face-to-face in the near future.



“Harnessing lived experience expertise is integral to health and social work education. It reminds us of the reality of the lived experience; the challenges of accessing care and support and, above all, provides evidence of what works. It is integral to improving the quality, relevance and impact on health and social care practice. Our students report that service users and carer involvement in their education has led to increased knowledge and understanding; ways of improving practice, enhanced resilience, opportunities for discussions and opportunities to gain feedback.”

Dr Mel Hughes



‘Our service users and carers describe themselves as the bridgebuilders between theory and practice; providing current, real-life experiences to help students apply their learning. One student said, “Hearing firsthand experiences are essential when learning how to give patient centred care. It really helps to remind us why we are doing this and the impact we have.”

Angela Paget



I took part in the session below in your Carers Week -

1. Partners as carers in Maternity services which I thought Bethany Connaughton presented very powerfully on and I could identify with a lot of the points that she raised.
2. Learning Disabilities – Caring through the eyes of an older person – again a very powerful and emotive journey from Anne Mallon as a carer for her daughter.

I thought the organisation of the event was very good and allowed plenty of time for interaction with the presenters and audience, well done to all the team.’

Peter Atkins

Collaboration with Community Partners

NI Young Carers – Action for Children



Judith Younger from NI Young Carers, Action for Children was approached by a parent of a child who attends the Young Carers Service and who was also a member of the forum.

It was a privilege to be a part of this forum to advocate and share the incredible work of Young Carers. The opportunity to explain the impact a caring role has on a young person and how it affects their lives is something Jude is deeply passionate about. The approach which Jude used to present this information was via personal videos which had been recorded by young carers themselves and a short poem that was written and narrated by another young carer. This allowed the audience to resonate with the issues many young carers face daily. Some of the issues highlighted included family support, friendships, education, socialising and how each young person was impacted differently but all with the sole purpose of caring for someone they love. We recognise that Young Carers are vulnerable to missing opportunities and experiences other young people enjoy and this was a fantastic opportunity to share this information within the forum.

Working with all the staff and members within the forum allowed Jude to feel at ease and comfortable to share her own firsthand experiences with the group. The staff were excellent with communicating directly with Jude and the Young Carers service.

During carers week we worked alongside the young carers we support to give them a platform to share their experiences of being a young carer. This was demonstrated by developing video content which was then published on our social media pages. By doing this, young carers had a means of having their voices heard and ultimately raise awareness of their roles as carers within our society. The PCEP Forum was instrumental in the development of this content providing support throughout the process.

It is the intention of the NI Young Carers Service to continue to support young carers in raising awareness of their caring role. We will continue working alongside key stakeholders such as schools, policy makers and indeed the PCEP forum who are in a unique position to support future Nurses and Midwives in identifying young carers and ensure they can access support at the earliest opportunity. We hope within the coming year to return to the PCEP forum and the school of nursing and spread more awareness about this in topic helping professionals within the health sector to use their voice to advocate for a marginalised group within our society.

Written by Aisling Reynolds

Service Co-Ordinator – NI Regional Young Carers

Action for Children, Loughshore House, 10 Heron Road, Belfast, BT3 9LE.

Public Health Agency (PHA)



Engaging with QUB Patient and Carer Education Partnership (PCEP) Forum has been a huge honour and privilege for me. I heard about the forum through a colleague in QUB and given the importance of service users in shaping healthcare design and delivery I was really keen to meet the members; I wanted to hear their experience of health care and seek their support for my work going forward as well as to offer my support to them where possible.

My meeting with the forum was profoundly positive, uplifting and informative. I was

astounded by the diversity, the breadth of experience and the palpable passion to work alongside healthcare professionals like myself to improve the quality of the health services we deliver and most importantly the service user experience.

I was struck by the support provided to the forum by the QUB team who have grasped the absolute essence of supporting true service user engagement in an authentic and meaningful way, seeking and providing opportunities across the system for influence.

The pinnacle of my engagement this year was being asked to contribute, during Carers Week in June, to an interview with one of the forum members who talked about his experience of caring for his wife who has dementia; what an amazing man, what a humbling and privileged experience for me, I learned so much in that short conversation!

In conclusion my engagement with the QUB PCEP has been a rewarding experience at every level enriching my perspective as an Assistant Director of Nursing in the Public Health Agency. I now view the forum as part of my network of influencers and look forward to strengthening our partnership and collaboration into the future.

Sandra Aitcheson, Assistant Director Nursing

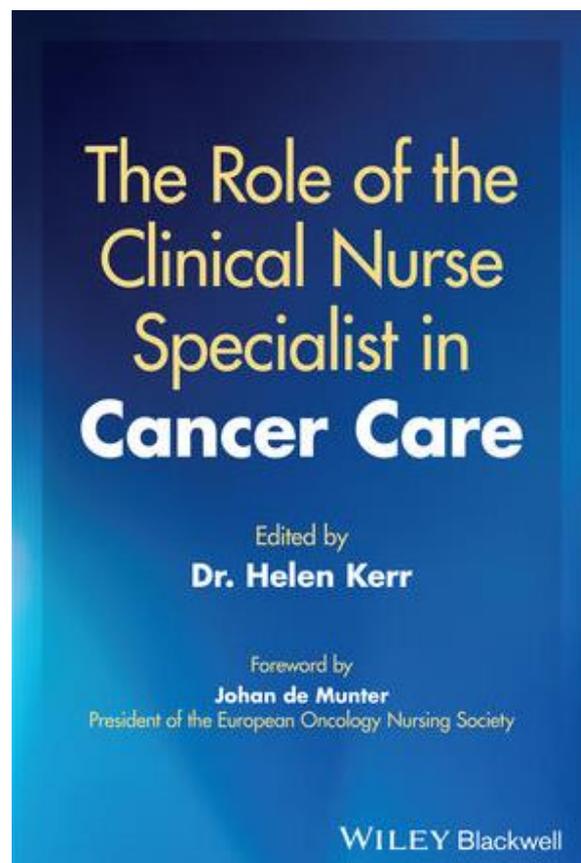
Public Health Agency



PCEP Member Trevor Wightman's involvement in writing a chapter in a recent book, "The role of the Clinical Nurse Specialist in Cancer Care".

I am editor for a book entitled 'The Role of the Clinical Nurse Specialist in Cancer Care' due to be published by Wiley Blackwell Publishing in September 2023. There are sixteen chapters in this book, and it aims to provide some insights into developing the various aspects of the role of the Clinical Nurse Specialist in providing holistic care for people with cancer and their families. Many of the chapters are co-authored by a Clinical Nurse Specialist and an academic with a clinical background in cancer care. Two of the chapters focus on the lived experience of cancer, one from the patient's perspective and one from the carer's perspective. I invited Trevor Wightman, a member of the Patients and Carer Education Partnership (PCEP) at the School of Nursing and Midwifery, QUB, if he would consider authoring a chapter in this book related to his role as a carer for someone who had been diagnosed with cancer. Trevor willingly accepted and kindly shared his experiences as a carer, with a focus on the contribution of the role of the Clinical Nurse Specialist. This is a crucial chapter in this book as it provides insights into the carers experience and how the Clinical Nurse Specialist can best support these individuals. I would like to sincerely thank Trevor for his willingness and openness in sharing his experience.

Dr Helen Kerr





PCEP Forum Celebrating Carers' Week from 5th - 9th June 2023

'Recognising and supporting carers in the community'

After the success of last year's event the PCEP Forum chose to hold online lunchtime daily sessions. This yearly event is organised by the members of the Forum and each session was very well supported by staff, students, trust partners and external guests.

Each day followed a different theme for all the fields of Nursing & Midwifery. The sessions were conducted as an informal chat between staff, PCEP member's and external organisations which gave the audience a true insight into what it is like for carers, families, and service users on a daily basis.

Monday 5th June 2023 - Midwifery – 'Partners as carers in maternity services'

Dr Lorna Lawther, Lecturer QUB, Ms Bethany Connaughton, PCEP member and Mark Connaughton, Partner, Ms Imelda Smyth, PCEP Member

Bethany and Lorna discussed the role of partners as carers during specific periods of the maternity journey through the experience of Bethany's partner Mark Connaughton.

Tuesday 6th June 2023 - Children and Younger Persons - 'Caring through the eyes of a younger person'

Ms Lucy Simms, Teaching Assistant QUB, Ms Judith Younger, Family Support Practitioner, Action for Children Young Carers Service and Ms Imelda Smyth, PCEP Member

Judith and Lucy discussed the challenges that young carers face through family circumstances. Jude has worked with Action for Children's Young Carers Project for 11 years, working across Belfast, South-Eastern and Southern Trusts with a variety of families from many different backgrounds.

They chatted about family experiences and highlighted the support available from Action for Children as this is often hidden in society. It was lovely to hear from the young carers.

Wednesday 7th June 2023 - Mental Health - 'Bereaved caregivers of people with serious mental illness'

Mr Iain McGowan, Senior Lecturer, QUB, Ms Marianne Tinkler, PhD Student and PCEP Member and Dr Scott Peddie, PCEP member

Iain and Marianne had a conversation with regards to bereaved caregivers of people with serious mental illness and Marianne spoke passionately about this project she is undertaking.

Thursday 8th June 2023 - Adult – ‘Caring for a loved one living with dementia’

Dr Gary Mitchell, Senior Lecturer QUB, Mr Brian Fitzsimons, PCEP member and Ms Sandra Aitcheson Assistant Director Nursing Adults and Older people, Public Health Agency

Gary and Sandra spoke compassionately with Brian who gave a recount of his personal odyssey as a devoted husband, steadfastly supporting his wife through her journey with dementia. He eloquently traced his story, commencing from the pre-diagnosis phase, navigating the complexities of caregiving, and ultimately arriving at the pivotal juncture of transitioning to long-term care.

Friday 9th June - Learning Disabilities – ‘Caring through the eyes of an older person’

Ms Ailish McMeel, Lecturer QUB, Ms Maria Somerville, PCEP member and Anne Mallon, Carer

Maria and Ailish chatted with Anne who shared her perspective on her life journey as a carer for her daughter Kelly Ann which spans over decades.

Anne shared her experiences of years of campaigning for better services for people with Learning Disabilities and their carers.

Below are some quotes from the sessions: -

"Informative and eye-opening presentation I am in awe of Bethany and how strong she is discussing a very sensitive subject. well done and thank you for sharing".

"Thank you for the awareness of how Action for Children is a great resource to support children who are carers. I have learned so much today. Great to hear the voices of the children and their real-life experience as being a carer. "

"I work as the carers commissioning officer for BCP Council, I cared for my father throughout his cancer diagnosis last year until he past away in September and I agree that there are a lot of gaps and a big lack of support toward the end of life and after, particularly a lack of communication and recognition in hospitals and preparing for what happens after death and what support there is".

"Thank you, Brian, for sharing your story, you are an inspiration, and I will take your advice on board in my journey as a student nurse. Thank you"

"As a Learning disability nursing student, it has been brilliant to hear the perspective of the carer today. Anne has really highlighted for me the importance of including carers fully when caring and supporting a person with a learning disability. Thank you so much for talking to us today. The work you have done over the years to ensure learning disability services are available and fit for purpose is awe-inspiring."

Involvement in Research

Co-design of and evidenced informed service model of integrated palliative care for persons living with a serious mental illness.



My name is Marianne Tinkler, I am a Macmillan Palliative Care Nurse currently undertaking a PhD Fellowship at Queens University Belfast and a proud member of the Patient and Carer Education Partnership (PCEP) forum.

I have been a qualified nurse for the past 28 years and half of that has been within palliative care. My MSc in Supportive and Palliative Care involved persons with schizophrenia in the last days of life in 2018, alongside grounded clinical observation, has brought me to this point in tackling inequalities within palliative care and mental health for persons with serious mental illness. I am to address this by completing PhD Fellowship with the Co-design of an evidence informed service model of palliative care for persons living with serious mental illness.

Globally, close to one billion people are living with a mental health disorder and is noted to be one of the most neglected areas in public health (WHO 2021). If you live with a severe mental illness, you have a greater mortality risk than the general population, experience health inequalities throughout life and represent a vulnerable, under-served and under-treated population. With the access to palliative care becoming a public health priority set to double over the next 4 decades, (Sleeman et al 2019), where does this leave this population and their basic human right to accessible palliative care?

The aim of the study is to co-design an evidenced informed service model of integrated palliative care for people living with a severe mental illness. This qualitative sequential study underpinned by interpretivism will consist of 6 phases and an expert reference group will inform all aspects of the study. 1. Establishment of the expert reference group. 2. Systematic literature review. 3. Semi structured interviews with bereaved caregivers. 4. Focus groups with service providers. 5. Co-design service model. 6. General recommendations to inform education and policy, further research, and service development within practice areas.

Reducing inequalities experienced by people with a severe mental illness is embedded in the National Health Service Long Term Plan. Future policy and practice will benefit from a better understanding of the needs of this client cohort and the development of a co-ordinated integrated care pathway to facilitate timely access to palliative care.

Within the PCEP at QUB I hope to be a voice from student/research and lived experience of mental illness. I hope also to bring a voice of bereaved caregivers of severe mental illness which is lost within the area of palliative and end-of-life care generally.

Interests

Palliative care//mental illness//palliative care and mental illness inequalities//health inequalities//privilege//social justice//improving access to palliative care for people with serious mental illness and addictions//speaking truth//vulnerability//storytelling//qualitative research.

Our Plans for Next Year



Our vision as a School is to provide a state of the art, inspirational learning environment that equips the next generation of nurses and midwives with the knowledge, attitude and skills to deliver and lead care in the modern healthcare arena. We work collaboratively with our students, practice partners, service users and carers and commissioners to develop competent, critical thinkers and solution-focused graduates that meet employers' needs for a digitally capable and highly skilled workforce that is representative of the public they serve. Established over a decade ago, PCEP is recognised as one of the Schools main cornerstones to support the achievement of this ambition.

Students and staff are encouraged to seek out the service user/ carer experience, as a valuable tool, enabling them to deliver person centred health care across diverse contexts. PCEP is one of the most powerful forums we have in the School to ensure that we do not lose sight of this central nursing and midwifery premise.

Co-production is a hallmark of the School in all its education and research activity, and service users and carers are engaged at all levels making a significant impact to what we do. This hallmark of our School has drawn recognition at national and international levels. PCEP continues to grow and evolve and provides rich connections that enhance the delivery of education. I hope you all feel valued as core members of our team and drivers of our students' educational experience.

The year ahead is an exciting time for PCEP and the School with the increased awareness and demand for service user and carer involvement in education. The opportunities are vast in terms of sharing best practice and building relationships with other Higher Education Institutions. The first PCEP conference on 22nd April 2024 will provide an ideal opportunity to showcase the work of the forum to a wider audience and build on local, national and international connections.

On behalf of the students and staff I would like to thank the forum for their continued commitment, passion and drive to support and improve the education of the future nursing and midwifery workforce.

Thank you from the bottom of my heart for all you do.

Professor Donna Fitzsimons, Head of School

The Patient and Carers Education Partnership Forum's plans are: -

- ❖ Engage in all aspects of the School
- ❖ Involve Professional leads in the planning of PCEP involvement
- ❖ Assign co-ordination role to field specific members, who will manage and report activities and engagement to Forum
- ❖ Engage with students by attending Student Voice Committee (SVC)
- ❖ Share best practice by building partnerships with universities across Ireland, UK and Internationally
- ❖ Organise a Conference to showcase best practice in Patient and Carer Involvement in Education

Contact us

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