



Laura Collins

Professional Background:

Nursing background, management graduate, university disability mentor.

Expert-by-Experience:

Full-time Family Carer for past 34 years. Currently supporting two adult children.

Decades of voluntary advocacy work and activism in support of family carers and those with disabilities - of which 25 years formally representing family carers at local, regional and national levels.

Current P&P Involvement:

Member of a number of carer and /or disability voluntary groups Reg. Unscheduled Care PPI Group
Reg. Social Work Strategy PPI Group (Citizen’s Forum)
Reg. Social Work Research and Service Improvement Strategy PPI Group
Integrated Care Partnership - Carer Representative
Belfast Trust - PPI Reference Group, Carers Reference Group, Carers Strategy subgroup
PCC Membership Scheme –carer member Cochrane Collaboration - lay member

Research Interests:

Early intervention on Autism Mental health pharmacology
Commissioning for integrated health Designing multi-morbidity services Older People and healthier ageing Carer pathway development Reducing health inequalities



Jean Dunlop

I retired from Ulster University in 2015. My working life was spent in the Library on the Coleraine Campus. As a front line member of staff I was often approached to participate in research projects and trials. This has eventually led me to PIER.

Most of my life I have also been a lay rep for my Union, Unite, and this, along with other volunteer roles, enabled me to act as an advocate for those needing support in a variety of aspects.

Since retirement I have sought to continue that interest through the Patient Client Council and as a member of the Integrated Mobility Transport Advisory Committee, IMTAC.

My passions in life are my dogs and cats and travelling, especially to the former Soviet States and to watch wildlife in their natural environment. I consider myself very fortunate to live in a rural environment on the North Coast.



Alan Ferret

I live in Belfast, am a Business Studies graduate and an associate member of CIPD. Previously I was a Director in an HSS Trust and have also served as a School Governor in an integrated primary school in Belfast.

Current PPI involvement

- Member of a study examining Telemonitoring in health care
- Member of the steering group which is responsible for the Nicola project (a longitudinal study of ageing)
- Member of Panel appraising Enabling Research Awards
- Member of a panel appraising Knowledge Transfer Requests
- A user representative on the panel for Doctorate of Clinical Psychology applicants, QUB

Research interests

- Use of technology in the delivery of health and social care
- Healthy living issues including the benefits of exercise and issues around obesity
- Conditions concerned with ageing
- Mental health issues including psychology research and the use of different therapies
- Issues around emergency services in health care



Margaret Grayson

I have been involved in partnering with researchers and part of HSC R&D Division PIER group since 2010 and a facilitator for Building Research Partnerships.

I am Chair of the Northern Ireland Cancer Research Consumer Forum, and a Personal and Public Involvement (PPI) representative on the NI Cancer Trials Network (NICTN) Co-ordinating Centre Executive Committee, NICTN Steering Group and Belfast Cancer Research UK Centre Governance Board. I am also a member of several study steering groups and a co-applicant on an NIHR clinical trial.

Nationally I represent NI on the National Cancer Research Institute PPI Steering Group. I am also an Involvement Coach with Cancer Research UK and a member of the Patient Advisory Panel for the £20 million Grand Challenge Award.

In April 2018 Margaret was awarded the Iris Colvin Lifetime Achievement Award for Health and in June 2018 was awarded an MBE (Member of the Order of the British Empire) in the Queen's honours list.



Jenna Hill

I graduated from Queens University Belfast in 2014 after completing a BSc in Psychology and MSc Atypical Child Development. Whilst studying I devoted a great deal of my time to completing voluntary work with Autistic young people and youth offenders. It was this experience that encouraged me into a career in social care. For the past three years, I have worked for a domiciliary care company which provides care to the elderly and/or those who have a learning disability in their own homes and I am currently the manager of the company.

I am currently working to expand my knowledge of social care and want to educate others on the challenges we face on a daily basis within the sector.

My research interests include:
Older people and healthier ageing
Use of technology in health and social care
Psychological therapies"



Aidan Kearney

I am Aidan, I have an extremely rare and aggressive bone wastage disease.

Before being involved in a research trial my quality of life was poor, there was no hope and nothing but bad news.

After being involved in a clinical trial my life has changed massively, I am fitter, stronger and healthier than ever before in my life. Being involved has given me a far better quality of life that I could of only dreamed of, I used to worry about the future and how fast I was deteriorating. Not now the future is bright and I have hope which I never had before.

Research did not just change my life it saved my life.



Gordon Kennedy

I am a retired civil engineer, My introduction to PPI began under another name. My wife Phyllis was diagnosed with Alzheimer’s disease over 20 years ago. This led to Phyllis being invited to participate in the clinical trial of a drug called Aricept, the first possible drug treatment for the disease, which was being carried out by Prof Passmore’s team at Queen’s. This led a few years later to Phyllis participating in further research projects into the illness. One such project was being funded by the Alzheimer’s Society and it involved their newly formed Volunteer Research Network. The Network is made up of people either with dementia, or who have direct experience of caring for people with dementia. As Network members, we prioritise the aspects of the disease which the Society should be funding, score the four page lay summaries which all grant applicants are required to submit and sit on appointment panels. In addition, three Network members are appointed to all successful research proposals as monitors. Because of this requirement, Prof Passmore invited me to be one of the Society’s monitors for his new project, which was rather back to front, as it was because I was asked to be a monitor that I joined the Network, rather than the other way round!

That invitation was the beginning of a 15 year journey as a lay participant in dementia research, a journey which I have found to be both enlightening and personally rewarding. It has also led me into a broader PPI journey. As the work which the Alzheimer’s Society’s Volunteer Research Network had been doing, was in effect PPI in action, I was invited to participate in the steering group. That too has been a privilege, in sharing and learning how properly implemented PPI can be of real benefit not only to the users, but also to the researchers, as they seek to find cures and at the same time, improve the care and treatment of all users of the Health Service.

One recent, very positive development of the PPI role, has been in meeting with researchers at the formative stage of their research proposals. There is a real risk that involving service users in research can simply be seen as putting a contact name in the PPI section of the grant application form! People with the specific illness being studied, and those caring for them, have unique insights and experiences which, if tapped into, can enable researchers to better focus and develop their projects. Early involvement with PPI representatives can allow this to happen, thus leading to better research and better outcomes. That, in my opinion, is what PPI is seeking to achieve.

Most recently I have participated in the public announcement of the Join Dementia Research register, which has been set up in Northern Ireland to enable more people to participate in clinical trials. Research is an exciting journey with new technologies enabling new discoveries and insights to be made across a broad range of disciplines on an ongoing basis. As a lay person, it has been my privilege over the last 15 years to participate in some small way in that journey.



Trevor Lyttle

My professional background is in libraries and information services which included managing the Medical Library and Information Services for Queen’s University and the Health and Social Care Services in Northern Ireland. From this has come a strong interest in quality assured care and evidence based practice and I currently serve as PPI member of the Northern Trust Research Governance Committee.

I have a strong personal interest in children’s services as I am an adoptive parent and have been a foster-carer. Currently I am an independent member of the Northern Trust Foster-carer Registration Panel. Since retirement I have been working part-time for AdoptNI, a small charity which helps adopted adults to find out about their original family leading to reunion in the right circumstances.



Ignatius Maguire

I am a Housing Manager with NIHE in Fermanagh & Omagh, with over 37 years service in Housing.

I was a member of the Western Health Council for many years until the Health Councils were disbanded in 2009 and almost immediately I became involved in PPI.

I have sat on the Doctoral Fellowship Panels (short-listing and interviews) every year since 2009 and I have assisted with other funding applications when requested to so do.



May McCann

I lectured in Social Anthropology at Queens University Belfast, (1973-1998), specialising in the fields of Diversity, Women's Studies and Irish Studies. On early retirement I moved to the community and voluntary sector, working in the areas of policy, equality and peace-building, especially in the Women's Sector where previously I had volunteered for many years. As is often the case with carers, my life experience led me increasingly into advocacy; personal advocacy for, or with, loved ones experiencing emotional distress and collective advocacy for transformation in mental health care and treatment.

I was an active member of the Mental Health Carer's Reference group throughout the period of the Bamford Review of Mental Health and Learning Disability where I had responsibility for writing responses to the Expert Group's documents: I also sat on its Equality and Human Rights Expert Group. Since 'Bamford' I have been involved, as carer representative with, the Royal College of Psychiatrists, sitting on the Carers Forum and on its Revalidation, and Curriculum Development, and Continuing Professional Development, Committees in London; the Department of Nursing and Midwifery and Department of Psychiatry in QUB; and the Participation Panel in Psychology, QUB.

I have been, and continue to be, involved in a range of strategic planning and service improvement bodies within mental health and social care, including, the Psychological Therapies strategy and implementation groups; the Social Work Research Strategy; DESR (Developing Excellence and Supporting Recovery) – the mental health nursing strategy implementation group; the Belfast Trust Recovery Group and Recovery College planning group. I acted as a critical reviewer on the recent Regional Mental Health Care Pathway, You in Mind, and am involved in the related documentation group, as well as the Review of Mental Health and Well Being Standards.

Throughout my careers I have produced papers, publications and given presentations in the areas of equality, human rights, service developments etc. with particular reference to diversity, gender and mental health and more recently in the related area of PPI (Personal and Public Involvement). In 2009 I was appointed by the Minister for HSSPSNI as a non-executive director of the newly established Patient and Client Council and sit on its Research Committee. I am also a member of the Bamford Monitoring Group (whose activities included participation as steering group member for service user-led research), and which I chaired 2011-14. I currently chair CAUSE, a peer-led regional charity which offers services to families, partners and friends caring for loved ones who have experienced serious mental illness.



Dermot O'Hara

I am a founding member of the Destined organization that provides services for 150 people with learning disabilities from two centres – one in Derry City and the other in Feeny County Derry and offers support to a number of individuals resident in the Tyrone and Donegal areas. Prior to setting up Destined I established the Derry branch of P.A.P.A. the autism group.

I have extensive knowledge and experience of the learning disability sector including the statutory and community organisations and has been involved in most of the strategic and policy consultations regarding the overall direction of service provision and support for the sector. The Destined model of service delivery is recognized for its good practice. I am currently involved in the establishment of a North West Centre for Learning Disabilities to be based in the landmark Foyle Valley Railway Museum in the city.

I am a member of the Bamford Monitoring group that was appointed by the Department of Health to monitor the implementation of the Bamford strategy across the five Health Trust areas.

My background was in finance, business and accountancy with a particular focus on enterprise development. I was the financial director of An Gaeláras during the development of its £4.5m Irish language Centre and am currently chairperson of the Outerwest Neighbourhood Partnership and also the Glen Development Initiative who are centrally involved in a development consisting of 80 housing units and a new community centre.

I am the current PPI representative on the Western Trust's Research Committee.

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|  <p>Tony Samworth</p> | <p>In England I worked as a Community Worker visiting people at home with mental health problems (1980's). I worked as a volunteer for the National Schizophrenia Fellowship (N.S.F.) in the 1980's. I used to run the drop in every Sunday afternoon. Volunteer for South Eastern Health and Social Care Trust from 2008 and help out at a day centre 2 days a week.</p> <p>Member of North Down and Ards User Trust Forum for over five years. Lay Member of Ulster Hospital Research Committee for over five years, involved in reviewing research projects. Lay Member of Infection Prevention and Control Committee, Ulster Hospital, Dundonald. Member of Public Involvement Enhancing Research (P.I.E.R.) for over five years.</p> |
|  <p>Kevin Synnott</p> | <p>I am married with two children.</p> <p>I retired from the Fire and Rescue Service (FRS) in 2013 after twenty nine years service.</p> <p>My service included operational roles in a number of different areas from Belfast to Omagh finishing at FRS headquarters in Lisburn. My role was head of the Operations Department with responsibilities for producing standard operational procedures, operational policies, coordinating Emergency Planning and Business Continuity activities.</p> <p>Since retiring I have been involved in a number of voluntary roles as well as trying to keep fit and healthy.</p> |
|  <p>Eileen Wright</p> | <p>My background is mainly in Finance and Education. I have been a company director for 25 years and am a former member of the Institute of Directors. Since then I have held a number of appointments in Education including: membership of the Southern Education and Library Board and Vice Chairman of the Finance Committee, 17 years as Chairman of the Board of Governors of Banbridge Academy, member of the Board of Governors of Ballydown Primary School in Banbridge, and am a member of the Governing Body of the Southern Regional College.</p> <p>I have served as a Lay Reviewer with the Regulation and Quality Improvement Authority (RQIA) and was part of the training process. I am also a member of the Board of Directors of Banbridge District Enterprises.</p> <p>I was appointed as a member of the Southern Health & Social Services Council in September 2003 and was serving as Chairman when it was subsumed into the PCC. I was a member of the Project Board for the new organisation.</p> <p>I am a lay member of the R&D Governance Committee of the Southern Trust and also of the regional body.</p> <p>I am the Lay Member of the All Ireland Institute of Hospice and Palliative Care Governance Committee.</p> <p>I am committed to representing the view and involvement of users of services in all aspects of health and social care, and in educations and am a volunteer in Craigavon Area Hospital and Southern Area Hospice.</p> |



Maggie Wright