



**Welcome from Chris Essen, Service User and Carer
Involvement Development Lead**

“This is a special edition of our Public Partnership Group (PPG) newsletter. We are presenting some of our group members’ experiences during this difficult and sad period that has affected us all in a variety of ways and sometimes has forced us to find novel ways of coping with it. I am introducing myself to some of you for the first time, under what I wish were better circumstances.

“Last November, I was delighted to take up my current role to lead the promotion, development and maintenance of patient, service user and carer involvement in the School. A few of you know that I have held similar positions at two other universities for nearly nine years. I helped to develop some of the regional and national involvement practice networks. My earlier career background was in the voluntary sector, but I also supported patient and public involvement within the NHS, and carried out collaborative research covering the fields of mental health, employment, housing and welfare reform. Throughout my career I have come to recognise that listening to the stories of those most affected by an issue, along with engaging in a reflective dialogue with them, can

powerfully enhance the learning of professionals, leading to better practice and better outcomes. I am working proactively with the School to further harness this power, building upon the great work done so far.

“Even without this unexpected pandemic, development work inevitably involves some small changes. One of our ambitions, moving forward, is to increase the range and amount of public involvement that occurs. In order to facilitate this expansion, I have been working with colleagues to strengthen the systems that support our work. Alison Morris continues in her valued role coordinating the delivery of involvement, of course. With Christine Rhodes, the School’s Strategic Lead for Involvement and the PPG Committee, we are together aiming to ensure that programme teams identify, well in advance, the key opportunities for meaningful involvement within their curricula. This forward planning will allow us to capture all of the relevant information in good time and communicate it to PPG members.

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“It also means that we will be able to use targeted recruitment of new members, while avoiding the possibility of members repeating work with the same group of students.

“The plans do not end there. Adding to what we have achieved in response to the lockdown, I would like to see PPG involvement in much more online learning activities, even though we hopefully will return to some semblance of normality. With your help, we are aiming to improve the training, supervision and appraisal offered to members. In the meantime, I wish you good health and look forward to one day meeting with more of you in person.

“I am usually available during the first half of the week, crossing over with Alison on Wednesdays. She is generally available for the rest of the week. You can contact either Alison or myself by emailing our team email address (hhs_ppg@hud.ac.uk).”



Note from the Editor



**Rob Moriarty, Service User
and member of the PPG**

“On behalf of everyone at the PPG, we sincerely hope this latest issue finds you managing to cope through these extraordinary times. Never have we been more in the same boat at the same time. So if we were ever to encourage empathy for others and their situation, it would most certainly be now.

“The eagle-eyed amongst you will notice a newsletter should have been out by now. The truth is we had everything ready to go just before the nation went into lockdown. I might be biased, but it was a cracking issue full of content that I’m sure you would’ve all thoroughly enjoyed reading.

“Just as the University has been adapting to a new life online, so has the PPG. We held our most recent quarterly meeting most on Zoom which worked incredibly well, and we engaged with students on it too. We discussed the ongoing involvement and potential future opportunities, and all agreed simply pushing the newsletter we had ready would have felt completely out of place with the current pandemic.

“We felt it would be far more useful for you all to read a snapshot of what life is like for many of our members, many of whom are either shielding or in other high risk categories.

“As more contributions come in we will publish additional issues more frequently than normal, so you can get a true flavour of what it’s like for many of us with additional circumstances and needs as we live through this.

“Stay safe, stay well and happy reading.”



About the PPG



The School of Human and Health Sciences believes it is of great value to the education of its students by involving a wide range of people who have experience of health and social care. This includes users of services, their immediate relatives or carers. Such involvement in education and research is an opportunity to make a lasting difference and influence future health and social care.

‘Real life’ experiences can help students understand the needs and expectations of the individuals they will be working with and enable them to develop the right values, knowledge and attitudes to support their client group. In doing so they are ultimately putting the person at the centre of their care. Students gain a better understanding from ‘Experts by Experience’ of what it is like to be on the receiving end of health and social care. Working alongside academics, it helps students apply and relate theory and research to practice.

The PPG committee meet regularly to discuss

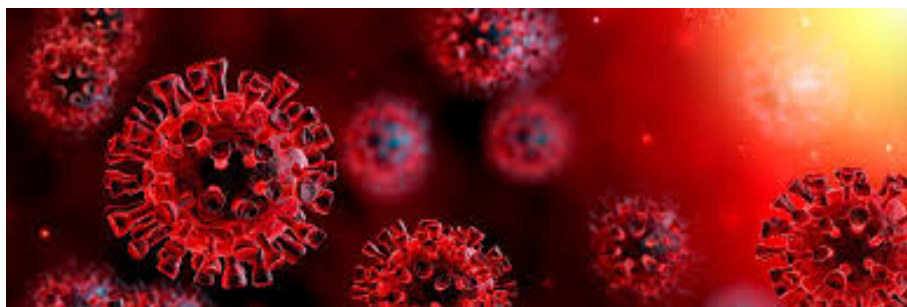
and formulate the overall direction and plans of the PPG. The network of individuals who are willing to share their experiences continues to grow and they can be involved as much as they wish.

Learning in the School is a joint endeavour between our ‘Experts by Experience’, students, academics and practice colleagues, working in partnership to achieve the goal of continuous improvement to care delivery.



A Perspective from Behind the Shield

PPG member Jackie offers an insight into what life has been like as one of the 1.5 million people being required to shield themselves until the end of June.



(Photo credit: www.gov.uk)

“It’s such a hard time for all of us right now. Lockdown is being eased, and everyone is out in the sunshine while we must stay in until 30 June and beyond to avoid the rumoured second wave.

“Some of you will know I am currently in hospital with the double whammy of Covid-19 and pneumonia. It’s day four for me, although it’s really day 11. I was ill in my nursing home that first week. I was not going anywhere near hospital but my pulse and blood pressure were too concerning.

“Care has been excellent first at Huddersfield Royal Infirmary then Calderdale Royal Hospital. Most people have taken my existing conditions into account. I’m on many more medicines now than when I arrived. Bricks of antibiotics arrive with alarming frequency. We all know the complications antibiotics can have on our bodies!

“I should be back at my nursing home tomorrow

on Sunday. There is the interminable wait for medicines and transport in sweltering heat first. I will have four weeks in my room till I can mix but that will take me to 18 June. The Shielding text from the Government didn’t arrive until a few days before hospital. It is typical right? For once another health emergency was not a surprise, but I’m so relieved I can say I have survived to tell more tales.

“Until we meet again. Jackie.”



A Day in the Life of A Carer in Lockdown

PPG member Janet Hargreaves describes an alternative perspective from behind the shield, with her experience of being a carer for her mum.



(Photo by Janet Hargreaves from her mum's window)

“At 6.40am, I drive through town relishing the lack of traffic and road works and enjoying the morning light, with the sun streaming across the skyline. It takes only ten minutes from door to door which is unthinkable in normal times. But these are not normal times.

“At 6.50am, I arrive at mum's place to relieve the personal-protective-equipment-clad Marie Curie night sitter who for the past nine hours has been kind, watchful, reliable, steadfast and supremely competent while I returned home to sleep in my own bed. Mum and I meander through the morning routine with tea, breakfast, bathroom, commode, and coffee in no particular order and with no urgency, dealing with health needs and crises as they occur. Since falling mum is not safe to live alone and since lockdown, we have no appointments, no commitments, no time constraints, no pressure, nothing to do but to live as well as we can.

“Her world is framed by the lounge window. The trees are in full leaf now. A magpie's nest,

painstakingly rebuilt twig by twig from last year's remains, was silhouetted against the bare branches just a few weeks ago, and is now hidden from view. The woman who runs turns the corner and jogs up the avenue, black ponytail bob bobbing on her back. We used to measure the weekends by her effort, now we see her daily. The school run is reduced to a solitary mum and child. The chatter of families and friends, the banging of car doors and the latecomers running to beat the bell are silenced. They are replaced by walkers in ones and twos. We invent back stories for them all and wonder if it will be warm enough for the man who always wears shorts to sit outside his door today.

“Time and place merge seamlessly. Now a game show or crime drama is either watched or more often slept through, with *Call the Midwife* as the exception that mum never sleeps through it. In the year of 1935 in Walthamstow, eight years old mum and cousin Joanie explored the streets, unaware of the disruption ahead that would send mum north to a new life with marriage and children, never to return. Now it is time for lunch.

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Mum's appetite is diminished but the planning, anticipation and eating of meals is a pleasure still unabated.

"At 2pm, one of mum's two carers arrives. Surrogate sisters who to my surprise and joy responded to our advertisement two years ago has made mum staying in her own home possible. I drive back to my husband and we make the most of the altered reality of our lives: the allotment, the garden and the arrived seeds with so much planning, planting and potting on to do, the crossword, coffee, queuing at the chemist, and what we shall have for tea. There are no holidays to anticipate and no outings. The outside world offers little distraction, but it is strangely difficult to settle to anything. The afternoon is punctuated by calls with community health, hospice and council staff who keep a watchful eye on us. Forms are filled in, claims made, milestones passed. In short sessions I continue with research, currently on the 1926 Select Committee report into the regulation and inspection of nursing homes. This was the first British attempt to scrutinise

a troubled sector. The report feels very relevant to today, illustrating the limitless ways that for-profit 'care' can exploit the poor, weak and old and the great difficulty of devising effective regulation.

"At 9pm, I return to mum and we drift through the bedtime routine, catching up on the day and anticipating tomorrow.

"At 11pm, once mum is settled, I snuggle down in the put-me-up bed with another day done. Like the lock down, I can predict that this will end one day, but don't know how or when. I suppress my panic that life will be impossible if one of us catches the virus. Listening to the rhythm of her breathing in the next room, I will myself to sleep until the early hours, when mum is likely to need a little help and then to sleep again, until the new day starts."

A Parent's Perspective

This is a mother's perspective of lockdown, work and children. Undoubtedly it echoes many sentiments just about every parent is currently experiencing.



(The Robot: Above is my eldest son's home-made robot made with passion. Boxes were brought to us by numerous delivery drivers.)

"I write this at 2am on a Thursday morning. It is a good time to work because the house is quiet, the children are asleep, and the dishwasher is at peace. My dishwasher and washing machine have been in overdrive for the last six weeks. My seven-year-old and eight-year-old are wearing about three different sets of clothes a day. I don't know why. I try to stop them but they just appear with different clothes on.

"We are stranded in our house without schools. I am a 'mum teacher', a part time worker from home and mostly on my own as my partner is out looking after other people as a key worker.

"It has been tough and exhausting, trying and yet amazing. It also lays heavy on me that there are people right now going through hell and that is also why I am awake at 2am. It's hard to deal with

sometimes so I try not to think about it. I am being busy. I noted today whilst typing something for work that I had to add Covid-19 to my dictionary in Word. Computers know about it now. It is everywhere. Out of this however, there has been some amazing things that I could never have imagined. Look at the headline on BBC news on the next page.

"My oldest child has a learning disability. He could have gone into school as he has an Education, Health and Care Plan (EHCP), but I didn't want him to. He's safe at home with me. Both of my children could have gone into school, but I want them home, being safe with me. I received work for my boys to do at home and my teaching qualification came in handy finally. I also spent a lot

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A Parent's Perspective continued...



(Photo credit: BBC news)

of time finding and thinking about resources particularly for my oldest, like speech therapy, writing formation, educational games online, making robots, Numicon and goodness me how brilliant YouTube is! I have discovered so many online lessons, live feeds, live broadcasts, and it's brilliant. We have also discovered Earth School via the TED talks people.

"My other son is in Year Two and loves learning. We are creating extra work together. We have made a lava lamp with oil, salt dough people, treasure hunts and have camped out in the back garden. Yes, I am enjoying teaching my children. I have learnt so much more about them and have found ways to help with my son's additional needs. Schools have called us weekly to see if we need help. We tried Joe Wicks too but were defeated by muscle ache and agony in the first week.

"My sons have had a few wobbles. They are not used to mummy being the teacher, and they want to go out and explore. I feel guilty we can't go to the park and they can't go on their bikes or scooter. I hope this time will end soon so they can enjoy their childhood again. It saddens me to see them being stuck.

"I also am enjoying my work, but I worry that I can't do much. I get interrupted a lot by my boys and I can't really focus on things for longer than an hour. I'm grateful that I work though as this has become my new 'me time'. I go upstairs and lock myself in my bedroom to work. It's either that or in the car.

"One of my sons has a birthday this weekend and he has been spoiled. I have fully embraced online shopping and deliveries. Where I would be without the help from all the people who bring things to our house: the post, the supermarket, Amazon, eBay, online shops, the milk man, the egg man, and the local police bringing Easter eggs to all the houses on our street where children live. I am so grateful for all these that they are doing for us.

"I dedicate this to all of the key workers out there cleaning, driving, delivering, caring, cooking dispatching. We are thinking of you and wishing you well.

"From me and my boys."

When Social Distancing Isn't An Option

PPG member Rob Moriarty describes what life has been like for him during the pandemic so far, and some of the challenges he has faced of continuing to employ his Personal Assistants (PAs) to support him 24/7.



**Rob Moriarty, Service User
and member of the PPG**



“Over the last 22 years I’ve grown accustomed to living a life with a high level spinal cord injury, depending on 24/7 support from PAs with all aspects of daily living: from personal and domestic to social and professional. Whilst many say Covid-19 will fundamentally change our way of life, it has so far reinforced many practices I’ve had in place with my care.

“Since taking control of my care in 2005, I’ve had to think through scenarios around when I employ my own PAs. What I am going to do if: I or the PA working for me becomes ill; the next PA is either ill or absent without a notice; either no one can cover or there aren’t enough backup options I can defer to and more. Each time after something has happened, I’ve learned from the consequences quickly and implemented changes that are fair to my whole team to prevent reoccurrences. I’ll admit I don’t always get the right answer, but I usually

find an option somewhere that works. Despite all that planning there are still ‘perfect storm’ moments every few years when everything that can go wrong does so at the same time.

“Contingency planning as part of my personal health budget (PHB) has helped me think through these ‘what ifs’. It is vital for so many people like me with no family nearby to step in when the wheels truly fall off the care package wagon. Now with the more than odd one off when backups might be needed, we don’t know how long this pandemic will last.

“So, what have I done so far? As I am not in the shielding group, I’m restricting ventures outside to essential supply runs, or fresh air where I know I can safely keep my distance from others around the town centre. I have a local supermarket nearby to buy food,

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When Social Distancing Isn't An Option continued...

and the Brexit planning last year means I have a three-month supply of all medications, at all times.

My existing PA team remains as they were, though I've taken on a tenth employee. All are working on slightly reduced hours to evenly spread work between them. It's always a fine balancing act to judge, better for them than being furloughed or unemployed and it gives me certainty that I've got enough options.

"I have a supply of personal protective equipment my PAs use for my healthcare routines, delegated to them as part of my PHB to eliminate my dependency on nearly 200 District Nurse visits each year. Having the choice, flexibility and control to do these when I want to rather than fitting in with their service has fundamentally changed my life, dropping to an average of seven visits per year. This has restored my sense of dignity and independence, allowing me to get on with life personally and professionally. I doubt if I would have been able to get through such a pandemic otherwise as each visit I have increases the chances of virus transmission.

"Understanding my vulnerability and the need to avoid any spread of coronavirus, my PAs have kept my flat cleaner than usual. They take their shoes off and wash their hands thoroughly every time they enter with singing happy birthday entirely optional. They steam clean floors and disinfect all work surfaces, bathrooms and regularly used items like light switches, TV remotes and door handles on every shift. They optionally leave a set of clothes they can change into the next time they're here.

"I've set up a WhatsApp group so my PAs can chat with each other more easily, particularly if any last-minute cover is needed. This is something I could have had in place years ago and definitely will keep going forward. As a first backup I've contacted six former PAs who've said they'd be willing to help cover if needed. It's a huge relief to know they could slot back into the team as they've already got the skills needed for this work, far easier than searching for new recruits which can take up to three months.

"I am hopeful that all these plans will help me continue living through this pandemic as independently as I have been over recent years. In all care packages I've had, my priority is to live independently of friends and family. I want them to visit when they choose to rather than out of a sense of obligation so they can get on with their own lives. This pandemic has highlighted just how well-timed and effective the personalised care and support planning process was when I moved onto my PHB six years ago. Without this, navigating my way through recent weeks just wouldn't have been possible."



Speaking for the Frontline



Laurette Tahmassian-Zarneh

“I am currently working as a Lecturer Practitioner. For two days a week I am based at the University, co-developing Speech and Language Therapy BSc (Hons) for the 2021 intake. At present this consists of working in my home office where I sit in front of my laptop to write documents and attend virtual meetings. The other three days of my week couldn't be much different. No longer with my creature comforts, I provide healthcare for in-patients in an acute NHS hospital, many of whom have a diagnosis of Covid-19.

“As a Speech and Language Therapist, a principal part of my role is to undertake the assessment and management of dysphagia. It is a swallowing disorder resulting from a neurological, physical, respiratory or psychological impairment of the oral, pharyngeal or oesophageal mechanisms. Although not solely restricted to, it can be identified through the anterior or posterior loss of drinks or foods, and an inability to masticate, coughing and / or choking. As a consequence, it is associated with risks of aspiration, dehydration, malnutrition, pneumonia, and reduced quality of life and mortality.

“When I undertake a swallowing assessment which predominantly consists of me trialing different consistencies of drinks and foods at the bedside, coughing may be generated. If drink or food enters into a person's airway, the body's involuntary mechanism is to cough it out before it could enter into the lungs possibly causing complications such as aspiration or pneumonia. As a result of this, our procedures have been recognised as an aerosol generating procedure (AGP). When coughing occurs, aerosols or small droplets are emitted into the air, which can enact as a possible route for the virus transmission. Therefore, in all direct patient contact, I wear full personal protective equipment (PPE). This consists of a specialised tight-fitting respiratory (mask), visor, full-apron and gloves.

“As you can imagine this means that I can become very warm and uncomfortable throughout my working day and can only see a limited number of in-patients due to the time it takes to put the PPE on and off, also known as 'donning' and 'doffing'. Most importantly

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Laurette Tahmassian-Zarneh in PPE

however, for the person we assess, it can cause challenges to communication we may take for granted, such as not being able to see my face or facial expressions, or lip-reading or hearing what I am instructing or saying. For someone living with dementia, this can be quite scary. We can use picture cards as long as they are laminated so that we can clean them down. Otherwise we have to throw them away to prevent any potential infection.

“However, right now this is something that is a certainty and a constant. It is in our professional body guidelines and supported by our Trust that we must wear appropriate PPE. In contrast, every other part of my day is unpredictable. When I arrive at work, our team may have had no referrals or be inundated from any ward, including the stroke unit. I then help to triage and prioritise the caseload to determine who needs to be seen on that day, which is based on various factors. When we attend a ward, we have to wear a general face mask and ensure that we sanitise our hands regularly. More than ever we have to work closely with the multidisciplinary team to ensure that people are discharged in a timely manner to prevent unnecessary prolonged admissions.

“Despite the uncertainty that we face, there is a sense of camaraderie that I have never really

experienced before. Although the needs of people with and recovering from Covid-19 are emerging, I have started to see the consequences of life-saving interventions such as ventilation, tracheostomy and / or oxygen therapies. These include potential swallowing difficulties, respiratory compromise impacting upon swallowing and communication, voice disorders and cognitive communication disorders. We are all in this together and no one really knows what each day will bring. What we do know however, is that we are all striving for the same thing to provide the best person-centred care that we can during what is potentially the most unpredictable healthcare crisis in our time.

“Of course, at the end of the day I change my clothes, wash my uniform and shower. It is only then that I can step out of my clinical role and into my other ‘job’ of being a mummy to my one-year-old daughter who has had a fun day at home with daddy. Despite everything that is happening in this chaotic new world that I am working in, nothing beats the smile on her face and the tight and warm cuddle that she gives me. Within this pandemic it is these moments that we must remember and cherish, and to hold our loved ones close.”

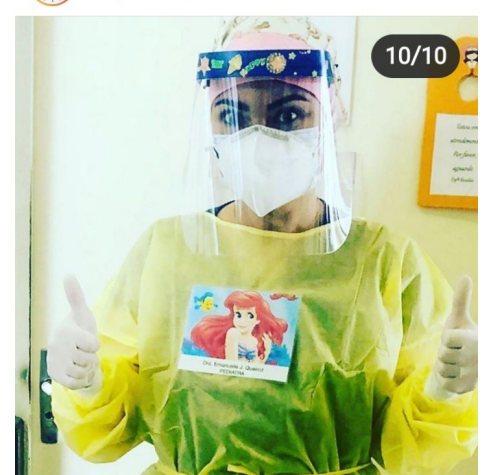
Behind Personal Protective Equipment (PPE) in Pictures

A look around the world at how health professionals are working hard during this pandemic to make the patient experience the best they can.



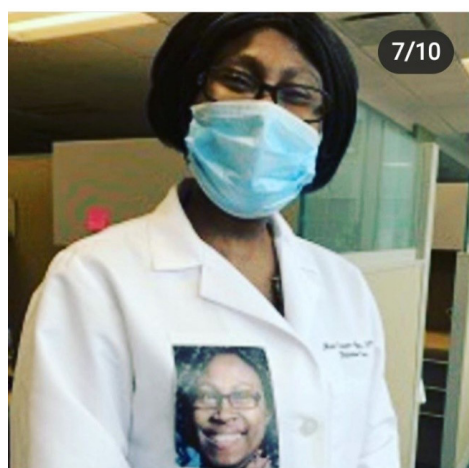
(Photos credit: @captain_wolf82 on Instagram)

A respiratory therapist named Robertino Rodriguez had a brilliant idea that brings some positivity to those with the coronavirus. "I felt bad for my patients in ER when I would come in the room with my face covered in PPE," he wrote on Instagram. "A reassuring smile makes a big difference to a scared patient. So today I made a giant laminated badge for my PPE. So my patients can see a reassuring and comforting smile."



(Photos credit: @captain_wolf82 on Instagram)

Behind PPE in Pictures continued



(Photos credit: @captain_wolf82 on Instagram)

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Behind PPE in Pictures continued

Nurses and doctors add cartoons to their face masks so kids won't be scared.



(Photo credit: Salford Royal NHS Foundation Trust on Twitter)

Medical staff in Beaumont Hospital wear their picture on the front of their PPE.



(Photo credit: LA URA Durcan on Twitter)

Behind PPE in Pictures continued

A nurse creates clear surgical mask to improve communication with patients.



(Photo credit: Faceview mask TM)

Molly Watts, a nurse in Southampton has written and illustrated a short story to help explain the coronavirus to children in a bid to reduce fears and anxieties around the outbreak.



(Dave the Dog is worried about coronavirus www.nursedottybooks.com)

The Weekly Visit from Lizzie

This is my weekly visit to see Mike. I'm outside the window with my PA, socially distancing in the rain, while Mike is inside. When I am not taking photos, I ring him on my phone and put it on speaker, so we can see and hear each other.



(Photo credit: Lizzie Walker)

The Mask Crusader

Josie, one of our PPG members, has become attached to her sewing machine and has been making masks for all her friends and family.



Contact the PPG

Alison Morris, Administrator of the PPG



Please contact Alison Morris if you would like to:

- Work with a Service User or Carer Group Member
- Find out more about the PPG
- Become a member of the PPG
- Obtain copies of any items mentioned in our newsletter
- Obtain copies of our previous newsletters
- Attend one of our meetings or social events
- Receive a large print of any items mentioned in our newsletter or the newsletter itself

Ideas for future publications

If you have any suggestions or ideas about what you would like to see in future publications of this newsletter please email these to Alison Morris.

Alison is based in the Harold Wilson Building, Ground Floor, Room 18 (HWG/18)

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