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Patient and public involvement and engagement (PPIE) in healthcare education and thesis work: the first step towards PPIE knowledgeable healthcare professionals

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ABSTRACT

In this Communication article, we share experiences of collaborating with members of the public during health education. We aim to inspire bachelor, masters and PhD students to engage with patients and the public during their undergraduate, graduate and postgraduate thesis work and to inspire educators to collaborate with patient and public involvement/engagement to develop and deliver teaching and offer their students opportunities to engage with patients and the public. We argue that when patients and the public are included in educational projects, such engagement will be an easier task once students graduate. We argue that including patients and the public in educational project work and encouraging reflections with a person with lived experience benefits students in terms of understanding the importance of reflection and validation, setting positive precedence for their future careers.

BACKGROUND

Throughout the paper, we will use the term 'patient and public involvement/engagement' (PPIE) as it is internationally representative for describing the process of developing health services and research with users of those healthcare services[1] and is not bound to any specific research tradition.

PPIE is increasingly recognised as instrumental to lifting the quality of research projects[2 3] while ensuring focus is on the relevance of the work produced. The reflections shared between researcher and patient partners when engaged in coproduced health research facilitate learning for all parties involved[4] and reflect ethical values, such as patient rights, fairness and democracy.[5] There are still challenges in implementing PPIE widely in healthcare research; Harrison *et al* had described: a lack of proper role description, expectation alignment and preparation of material as challenges for meaningful PPIE in a research project.[6] Many funding organisations and journals now require specific statements on PPIE[7]—perhaps pressuring researchers to embark on a PPIE journey with little motivation but to please the reviewer panel and no or little skills and knowledge on coproductive health research.[6 8] Wicks *et al*[9 p 1] stated in their 2018 BMJ editorial that 'One of the main stumbling blocks to coproduction of research with patients and the public is that professionals lack knowledge, skills and experience in how to do it'. Greenhalgh *et al* found in their recent systematic review 65 frameworks originating from 10 countries,[10] and guidance documents for involving patients and members of the public in health research are readily available from major organisations. Yet, a lack of local level guidance is still being reported, perhaps hindering practical implementation and leaving it to the individual researcher to make it work.[11] If PPIE opportunities are offered during education, these personal experiences could help the graduated researcher—removing an often-cited stumbling block for PPIE.

PPIE receives some attention in the education of healthcare professionals and organisations such as the General Medical Council[12] who recommend that: 'the development of medical school curricula must be informed by medical students, doctors in training, educators, employers, other health and social care professionals and patients, families and carers' p 33. But clear strategies of how to incorporate it and how to train it are lacking reducing efforts to personal initiatives of students and educators.[13] Bedside teaching has a long-standing tradition providing students opportunities to learn with, from and about patients—where patients are treated as clinical cases.[14] A stronger focus on involving patients as active agents in design and delivery

of healthcare education could make for more compassionate and humanistic health professionals[13] who find it meaningful to invite patients in research projects and their clinical work when graduated.

PERSONAL EXPERIENCES

I, AWK, the first author, have a background in nursing and am currently undertaking a PhD in health science in Denmark. In my master thesis (Master in Health Science at University of Southern Denmark), I investigated the opinions of mothers on the usage of their babies' blood spot heel test for broad scientific research. My supervisor, AJ, the second author, suggested I invited a mother from the target population into the study as a coresearcher both to train the PPIE process, and to strengthen the study by including a mother's perspective. Previously, I had been exposed to PPIE during a first semester master's module; AJ invited patients to share their illness experiences with the class. Their stories had a profound effect on us students and helped embody the covered theories on health and illness, and I was intrigued to try out a collaborative research process as part of my thesis. I reached out to a mother in my professional network, who was a nurse like myself and who was due to give birth during the project phase. I chose her as she was representative of the study population: she too would be exposed to the question of blood donation when giving birth and I knew from previous conversations that she had an interest in research. The mother and I shared decision making on protocol perspectives, interview guide, analytical discussions and putting the findings in a larger societal context, while I held responsibility for conducting interviews, performing analysis, writing up and progressing the thesis. Our conversations had a big impact on the interview guide and the questions asked. The coproduction process helped verify the analytical findings and ensured that it was not my sole interpretation. The mother could relate to the interview data and had another understanding of why mothers answered like they did approaching the data from a different angle. I interpreted their answers using theoretical lenses learnt. The mother went through the same experience of giving birth and receiving information on the heel blood spot test, she had an embodied experience of feeling the chaos in the days around postpartum and the overwhelming fear of making the wrong choices for your child—which were indeed reflected in the participating mothers' answers. Our conversations were imperative to develop a meaningful analysis with an understanding of both subject and context. Looking back, an even greater collaboration as cointerviewer and in-depth coanalysis would have enriched the study even more. I believe having the mother co-conducting the interviews with me, could have allowed a deeper exploration of answers as the mother could have reflected with the mothers being interviewed and helped break down the barrier between interviewees and researcher (even though I am a mother too, and worked hard to be relatable, I believe the professionality as researcher took over and it was also how the mothers saw me). In my present PhD work, also supervised by AJ, I have tried to use this learning, making a patient partner panel central to developing the project. The panel consists of five patients and relatives who meet regularly to discuss design, tasks, and progress of the substudies: a scoping review, an ethnographic study and Delphi survey. Currently, we are working on the scoping review where we have read and discussed a selection of articles together (protocol available at the Open Science Framework[15]); and we are collaboratively collecting data on the ethnographic study (protocol available at the Open Science Framework[16]). I have been fortunate to be able to liaise with AJ, who shared her expertise of many years of practical experience of PPIE in research and teaching, as I have needed advice and guidance on how to invite patients in and how to structure the collaboration. The challenges I have experienced have been eased by having this support available. Not being an expert in coproduction or in research, has meant that 'my' patient partners have also guided me in how they would like the partnership and their contribution to the research to evolve; together we continuously work out what works and what does not. Listening to AJ's experiences and seeing the changes the collaborations have made in my projects, have developed my way of working as a researcher and opened my eyes to the still substantial gap between researcher knowledge and the 'real life' of the people the research is hoping to improve.

PPIE AS AN EDUCATION IN ITSELF

When studying, our mindset is set to learn and trial different work methods and approaches. Being exposed to patient stories during training is already a focus within narrative medicine and nursing studies and can have a profound impact on students[17] as we (students at the Master of Health Sciences, SDU) have experienced personally. One of the acknowledged benefits of PPIE is that healthcare professionals gain new knowledge of living with a disease—as a researcher being interviewed about PPIE in their research project reflects: 'I began understanding much better the everyday challenges and lives of people affected by mental illness in different contexts and I am pretty sure, at least I would like to think, I have been profoundly influenced by that, in my own thinking about the sorts of questions I want to address as a researcher in the future' (Gupta and Roberts,[18] p 3). Gaining this understanding during medical and allied health professions (eg, nursing, midwifery) education, could influence the student's ability to see different aspects of a disease (referred to as illness experiences by scholars such as Arthur Frank; in for example The Wounded Storyteller[19]) and the impact it often has on affected people's lives. Students who have experienced various forms of PPIE during their undergraduate medical education report finding patient communication more comfortable, and

an increased motivation to learn and develop a more holistic perspective of healthcare.[20] Being exposed to these patient experiences or collaborating with patients in a professional capacity during education could create future healthcare professionals and health researchers that are (more) receptive to an open environment where knowledge is constructed together with a wide representation of stakeholders. And it supports the general development in society moving away from expert knowledge existing in a vacuum towards the morality of cocreating healthcare (and society) with the constituents.[21]

Reflecting on findings (whether clinical or research related) with a person with lived experience is indeed a relevant validating step and is not seldom overlooked in both qualitative and quantitative research as well as in the daily clinic, where validating discussions tend to happen only between academics and or with professional peers.[22] Developing critical reflection of one's own understanding with a patient is humbling as we have highlighted above, and it is our hypothesis that when working with patients as partners during our education, we are more likely to treat them as partners in the clinical and research setting too. Furthermore, this could aid counterbalancing epistemic injustice as has been found thriving in the healthcare system.[23–25] In a field where power has remained very much in favour of the health professionals,[26] PPIE could perhaps shift the balance of power more towards sharing in the education setting as it is somewhat removed from the statutory power in the clinical setting.[17 23]

As of yet, there are few opportunities to learn how to best establish and conduct partnerships with users of the health system during education.[27] PhD students have published how PPIE has had a positive effect on their own doctoral work as they found the collaboration aided the development of their learning journey towards becoming independent researchers. They recommend that it should be introduced during doctoral programmes within healthcare and social science.[4 28] We add to this that introduction could start earlier—during undergraduate, graduate and postgraduate studies. We have found that thesis work is a good opportunity to do so.

CURRENT CHALLENGES

McKeown *et al* pointed out how academic institutions may not have the infrastructure to support PPIE in a practical manner.[17] Assessing improvement in this area is difficult and we can only speak from our own experiences when arguing that now, 10 years later, there is still room for improvement in structural support. Providing patients with the necessary tools and skills to take part in a variety of research activities (eg, including access to and training in the use of specific software, creating a guest researcher accounts in order to access a secured email where project elements can be discussed, uploading documents on a shared protected server) is currently the sole task of the researcher. The financial system is not set up to process financial reimbursement and remuneration

for work done by patients and budget forms for funding applications often do not have salary posts for patients. The administrative system and university infrastructure is not (yet) ready to work with patients as research partners. If policy makers, universities and hospitals advocate for health research and health education with and for the public, we must create a setting where patients, service users, the public are treated more as partners, and thus have access to facilities that support them in the levels of cocreative processes they wish to embark on.

The importance of not wasting patient or public time must be noted and PPIE poses a risk, as not yet graduated healthcare professional may not be trained enough to engage patients and the public in beneficial or efficient ways. However, many thesis projects require interviews, observations, surveys or other interactions with patients and the public, and the time patients or the public may spend on PPIE activities should perhaps not be seen any less of a requirement. Dijk *et al* found in a recent review that patients and members of the public where motivated to participate in a variety of education tasks[20] and our experience is that patients and members of the public see benefits in helping to educate future healthcare professionals and are happy to be involved and have their perspective heard.

It is paramount that one is attentive that this is done in an ethically sound manner and the development of partnerships must be supervised by teachers with experience in PPIE.[27] As it is not common for academic staff to engage in PPIE practices yet, there may be a lack of skilled staff to support all future health students in PPIE activities. However, as researchers with years of experience still report lacking experience collaborating with lay persons[8] we believe it is important to practice during education. Obviously, this is not done overnight, and we suggest (1) identifying small steps of PPIE—for example, by inviting one patient in as a partner in a part of a thesis project and (2) starting with a level of involvement the student or teacher feels comfortable with to allow for time and energy to reflect on the process. Time to reflect will be more generous during education than when students' career kicks in, so prioritising reflection early is key. As teachers may be out of their comfort zone too, it is intrinsic that support for staff is available, for example, by creating a forum where educators learn from and reflect with each other. There is still much to learn in how to do this best, and we invite those with experiences to bring them forward.

Besides developing critical reflection, skills and a broader understanding of health and illness as we highlight above, involving patients and the public in the production of thesis work may also help students learn to be aware of language use, clear information delivery, project alignment with stakeholders, choice of relevant outcomes etc. as are some of the often-stated positive effects of PPIE.[4] This could prove of benefit in many future job positions not limited to the healthcare industry. Therefore, making PPIE an integral part of the medical

and or allied health professionals' education as a lecture topic and via opportunities to practice PPIE could create a ripple effect on broadening the areas of health research studied, increasing the person-centredness in healthcare and support relationships forged between the health system and the public for the future.

OUR RECOMMENDATIONS

► Teachers: Include patients and members of the public in developing curriculum and classroom teaching; offer students opportunities to interact with patients as teachers (eg, patients moderating group work, patients supervising students when practising interview skills, master thesis in coproduction with patient/the public).

► Students: Invite patients and members of the public to be involved in bachelor's and master's thesis projects. In the partnerships made: Put aside time for mutual and individual reflection practices.

► Institutional focus: Create infrastructural support to teachers, researchers, students and patients to fit a variety of PPIE activities (eg, access to online learning platforms, access to library, IT support, …).

► Create support networks for educational staff where they can share experiences with PPIE, to increase their learning and find inspiration for future PPIE activities.

► Create a network for patients and relatives as a platform to exchange experiences of being involved in educational work and strength skills required, while also being a support network in their role as patient and or carer.

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