

Testimonials of Lay Representatives on the HSC-PBPP

I have been honoured to be a member of the Public Benefit and Privacy Panel. I came to it with a background in information and intellectual property law and (many years ago now) in professional legal practice. What I enjoyed most was the feeling of being able to contribute to something of wider benefit to society. It was also fascinating to learn of and from the different perspectives of other members of the Panel. If you are thinking of becoming involved, I can only say “do it”. There is training and support: but I would also say that I am in no doubt that you will be able to make your own contribution from the start.

Abbe Brown

- **Why I applied**

I was interested in learning more about how information from my medical records, and those of fellow-citizens, is being used by researchers and commercial organizations to improve healthcare and wellbeing through discovery, innovative treatments, and enhanced service provision.

As a representative from the public on the new PBPP I sought to understand and contribute to overseeing the processes, with the aim of protecting privacy and helping to ensure the outcomes were transparent, functional and of public benefit.

- **What I could contribute**

By volunteering to serve on the PBPP I could, as an enthusiastic retired person with free time, use my knowledge to make a contribution to wider society while continuing to learn and develop my interests. I had experience from my voluntary work for the NHS, including being a lay representative for Healthcare Improvement Scotland, which involved serving as the lay member on hospital inspection teams and on the Scottish Health Technologies Group. I was therefore used to reviewing evidence at committee meetings and in contributing a lay/public perspective.

- **What I experienced during my service**

I was made very welcome by the professional members of the panel, and got excellent support from the administrative staff. During meetings I was encouraged to contribute to discussions, and as a result of reviewing research

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project applications I was able to emphasise and enhance the need for clear communication in lay terms concerning the potential public benefits of applications, and in the reporting of project findings.

The increasing ability of artificial intelligence (AI), cloud-based computing power, and autonomous algorithms to “mine” large information data bases (“big data”), such as NHS Scotland records, has raised issues about personal privacy, consent for use of personal data, security, commercial exploitation and public benefit. It has been very interesting to be part of the team evaluating applications for access to NHS data, and in helping to ensure that the work of researchers is efficiently facilitated and not hampered by undue governance. The dedication, flexibility, innovation and hard work shown during Covid-19 has been exemplary.

Benefits to the public, in terms of new discoveries, improved treatments, enhanced service provision, and reduced costs need to be balanced against the protection of personal privacy and ensuring public benefit from commercial gain resulting from use of the public’s data. Proper scrutiny requires input from various divisions of Scottish Government and an adequate staffing level for PBPP.

I have greatly enjoyed the stimulating experience of being a lay public representative serving on PBPP. Colleagues have been friendly, encouraging and very supportive. The work involves reviewing applications from a lay perspective – specialist knowledge is not required – and in reading committee papers, sometimes asking questions during committee meetings for clarification when issues appeared unclear to me. Papers were circulated well ahead of meetings, giving me plenty of time to review them. Similarly, deadlines for reporting on project applications were realistic. I found the work was well-planned, the quantity very reasonable, and undertaking this voluntary work did not affect my other activities.

- Conclusion**

Overall I have learnt a lot serving on PBPP and can thoroughly recommend being a Public Representative and team member on this interesting panel as it continues to develop.

Daniel McQueen

Public Representative (2015-2021)

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I became involved as a lay member due to my interest in patient data being used to benefit the public in a substantive way. Initiatives developed in partnership with clinicians, service users and the public should result in public health dividends which ultimately place patients and the public at the centre of care. The panel's two tiers work supportively to deliver decisions and this panel certainly punches way above its weight. We are a diverse group, including clinicians, researchers, information technology and governance professionals, lay members and Caldicott guardians who bring our expertise and independent views to consider proposals against set criteria. All give their time freely and are heavily invested in the concept of using patient data to develop public benefit whilst ensuring that patient trust and confidentiality is prioritised. Colleague's willingness to share knowledge, experience, and time in contributing to review of proposals is such a positive example of how individuals from a variety of backgrounds can collaborate and give life to research which may ultimately make a real difference to patient care. During this pandemic period of extreme pressure on all working in the healthcare environment, the group has persevered with tenacity to do the right thing on behalf of the public and patients and have provided rapid turnaround of many review requests for research related to COVID-19 in addition to the regular consideration of applications. I feel very privileged to have been part of this journey with the Public Benefit and Privacy Panel and have learnt much from colleagues from many different disciplines who have been so generous in sharing their knowledge.

Kenneth McLean 12/02/2021