

“I just don’t feel like myself anymore”: putting the patient’s voice into integrated care

Integrated care has long been the holy grail of health and social care. Yet it is as elusive as the mythical receptacle in terms of a universally accepted definition and delivery model. However, even though academics clinicians and managers may argue for their particular vision of integrated care, one thing is universally held true, that the realisation of integrated care must result in better outcomes and experience of health services for the individuals who use them. It is also almost unanimously accepted that the design and delivery of services must have the voice of the user at its core. Individuals using our health services should feel that they are seen as individuals and that the delivery of services recognises and strives to meet their needs, and is coordinated around them. But, dear readers, how best to give primacy to the voice of the user in integrated care service delivery and design – therein lies another elusive challenge. As a clinician with responsibility for the design of integrated care programmes, who has promised to do just that in the design of our integrated care programmes in Ireland, how best to do it remains as elusive to me as that legendary aforementioned vessel. We realise that we need to use multiple methods to capture the patient voice in a meaningful way and we have explored different quantitative and qualitative methods including surveys, narratives, stories and sensemaking technologies. So I read this paper with great interest and it has opened my eyes to a whole new area of research, health-based introspection. I must confess that this was a completely new field for me, and although I initially struggled with the terminology, after some remedial reading, I found myself immersed in a powerful scientific exploration of an incredibly personal journey. I was moved by the account and throughout found areas for improvement as a clinician, patient and for service design and delivery. I am grateful to the author for introducing me to a new area of social science to which I have previously been blind. My eyes have now been opened and I have a curiosity to understand more about this methodology, as I can see it as a powerful tool that can contribute at macro, meso and micro levels. Whilst I know not all patients will wish to or have the skills to perform this type of research, I have begun to realise the important role of qualitative social research methodologies in the pursuit of integrated care and its relevance and worth to a wide range of stakeholders and users of research. Yet it is a new field to many involved in integrated care. The challenge for social scientists and clinicians like me is how do we co-create relevant, worthwhile research that contributes to our shared goal of integrated care? I believe that integrating quantitative and qualitative research methods will lend depth and clarity to integrated care in a way that is synergistic and most importantly, gives the voice of the people we serve primacy.

