



PATIENT PARTICIPATION: a vital component

By Zamo Mbele

Clinical Psychologist

Director – SADAG, Editorial Board MHM

Johannesburg

zamombele@gmail.com

In the second quarter of this year I had the privilege to represent The South African Depression and Anxiety Group (SADAG) and South Africa at the fourth annual Global Patient Advocacy Summit. The summit was hosted and organised by Lundbeck in Copenhagen, Denmark with this year's theme; "One voice – together we will make a difference."

The aim of the Summit included convening patient advocacy groups and leaders from across the world, concerned with mental health and mental health advocacy. Patient advocacy was discussed and developed from many angles with

many experts sharing invaluable experiences for improving and constitutionally strengthening patient advocacy with global standards. What was notable for me during these conversations, workshops and guest speaker presentation was the unique though integral importance of patient participation in patient advocacy and patient treatment. While the latter assertion was also intuitively resonant, it became obviously glaring to me how the patient can often be unfairly relegated by both advocacy initiatives, healthcare leadership, and specifically by the treating team of professionals.

The errors of this way are many, however this approach ignores a fundamental question put simply, "Who has the most experience of being a patient?", and of course the answer is glaring – the patient. In this regard then, it's not counterintuitive to imagine and assert for the importance of patient participation in decision-making. In brief, the concept of patient participation understands the person's participation in treatment decisions made about his own health issues as key. Further, it involves the patient in sharing information, feelings and accepting doctors' and nurses' instructions.

This collaborative approach to treatment and management is not new in ethos, however it can be readily forgotten. What remains encouraging is the growing appreciation for the fundamental importance of patient participation and appreciating the patient as an expert too – well within their right to participate as a legitimate member of the multidisciplinary treating team (MDT). Globally, this no longer remains an opinion or option for patient treatment; instead it has become a political necessity in many countries and healthcare system globally.

The role and goal for patient participation and advocacy is a rightfully complex and exciting one with varying objectives and intentions. Simply, the role of giving the patient authority to inform and support patient centered agendas to inform decision making, improve patients' experience and no longer just reduce the patient to an object or units of data and rather allow for true collaboration.

David Gilbert, a former mental health service user, is an advocate in this right and a director of a few organisations promoting patient participation and patient and public engagement. Gilbert, who delivered an inspirational address at the above-mentioned summit, reflects on his experience as a patient where "I felt in a glass cage, to be shown off. Tick-box", with little authentic or dignified engagement with him as a patient and person. Gilbert reports using this experience as part motivation to lobby successfully for a seat at the MDT.

Studies showing that patient participation in treatment and management of psychological and psychiatric illness improves services and health outcomes significantly are now abundant. Beyond the qualitative data which is compelling health systems globally, the

quantitative data too has given weight to the rhetoric of "no decision about me without me", making it more than a tokenistic sentiment or phrase.

In the United Kingdom, the National Health Service (NHS), has recognised the vital importance of patient participation to the extent that they have installed patient leadership roles and positions, promote patient leadership programmes, and support patient innovators and entrepreneurs. The patient leader and leadership strategies mentioned earlier, are not intended to become the patients' voice, rather their role is to create sufficient channels and platforms for patients to have a weighted voice.

As a patient leader, Gilbert advises the following on the responsibility patients have in the patient participation collaboration; "As people who have trodden thin emotional ice, patients should be wise to the myth of 'expert' knows best. Our gift of vulnerability can inspire collective human endeavor. But patients don't know best. They know different. Together we can work for the best".

The requirement and responsibility for the clinicians,

healthcare providers, healthcare leaders and advocates is also complex and cannot be exhausted necessary outside of an extensive and robust engagement. However there is much to learn for the former group. What seems helpful in this process is the appreciation that learning and leading in treatment and management is co-produced with patients and carers. It's a process of building and fostering a dialogue within a secure and trusted relationship, which is mutual and symmetrical in respect and commitment as far as possible.

This co-consultative ideal needs however to be championed by those with the means to in the current disposition, and those include the former leadership group. At its core, patient participation in health care decisions is a commitment to valuing humanity, dignifying the patient, mobilising the patient in their own care, and regarding the individuality of the patient. As a growing legal right in global standards, patient participation is undoubtedly the international gold standard for healthcare systems internationally, and is at the future of avant-garde mental healthcare and advocacy. **MHM**

