

## Chapter 12

# Assigning People as Number One Priority: Engaging With Disadvantaged Communities in Healthcare Research

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### ABSTRACT

*Notions of the “expert patient,” user choices about where care is provided and by whom, and enhanced understanding between patients and healthcare workers for continuity of care all have implications for workforce planning and human resources. Modern health systems and care require a range of patient and community inputs if they are to be relevant for their users. However, partnering with disadvantaged communities for such purposes is not an easy undertaking. Such partnership efforts need to be premised on a participatory approach and face multiple challenges. Given the range of the stakeholders involved, the sharing of turf, risks, and resources that are usually part of such efforts requires careful consideration of all the partners. Further, there is always the possible exhaustion of the communities from being repeatedly over-researched, as well as the frequently encountered initial lack of trust between partners-to-be who have not previously collaborated. In such circumstances, the sharing of assets and a focus on enhancing the mutual capacities for a common purpose needs to be spelled out clearly from the start. Notwithstanding these and other challenges, over the past decade partnerships have become a frequent requirement for government and funding agency assistance. Research partnerships that incorporate community assets and values are among the defining approaches to social problem solving, where partnering has become the fundamental and strategic component of efforts aimed at promoting community health.*

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## **INTRODUCTION: PARTNERSHIPS AND THE RELEVANCE FOR HEALTH CARE**

Patients, clients or individuals are now assigned the number one priority for health systems and healthcare human resources planning (Hartzband & Groopman, 2009; Kobberdahl & Porter 2009). A prerequisite for such importance is that the views of patients will need to be heard and considered by healthcare practitioners, administrators, and policymakers. Indeed within the healthcare sector, recent decades have witnessed several features that have had a direct impact on confirming that people/patients are valued as the main and essential constituents of effective health systems. One aspect is that, with the move to patient-centered care delivery, patient engagement and patient education and the “expert patient” (where patients participate and are involved in their traditional “formal” care) has now become the centre-stage of health and social care systems. Such patient involvement comprises many activities, ranging from their involvement in individual treatment decisions and regimes, through patient consultation to the collective lobbying of organisations to influence health policy decisions (Andersson & El Ansari, 2008; Andersson, Tritter, & Wilson 2006). The aim is patient engagement and patient-focused interventions (Coulter, 2006; Coulter & Ellins, 2006). But health has traditionally been an expert-dominated field, and hence patient involvement has been a controversial development that has been resisted by some professionals (Shaw & Baker, 2004). Successful patient involvement builds on increased health literacy. Thus, interventions to build the capacity and health literacy of user groups are of growing importance (Kickbusch, 2001) and information is vital to make choice meaningful (Godolphin, Towle, & McKendry, 2001). Indeed health systems will need to provide a great deal of information to users of these health services. In health care, efficient information management is fundamentally critical to assure high quality and

cost-effective patient care (Jaspers et al., 2000). All these features present challenges to healthcare systems and to the traditional role of healthcare professionals.

A second aspect is the significant growth in choices about where care is provided and by whom: the provision of non-traditional care by non-traditional practitioners (e.g. using a variety of complementary therapies), and a range of community care services (Mavundla, Toth, & Mphelane, 2009; Zavrashvili et al., 2009). This has implications for health information, human resources and workforce planning, where informed patients provide inputs into decisions that are mutually agreed upon between them and their practitioners. A third challenge is the aging population, with the corresponding increase in chronic diseases, long-term conditions, and various extents of a range of disabilities. In such situations, the patient is not a transient client but one whose self-management skills are critical. Thus patient knowledge and information about the condition(s) is vital and patient-professional understanding for care continuity is critical (Greenhalgh, 2009; Griffiths, Foster, Ramsay, Eldridge, & Taylor, 2007).

All these challenges and demands have manpower and workforce implications. On the one hand, there is a definite increased need for well-educated medical and health informatics specialists (Jaspers et al., 2000). This requires proactive initiatives to train graduates in information and communications technologies that are increasingly needed in the healthcare field (Jaspers et al., 2000). National health care systems are increasingly required to deal with global problems and solutions (Ball, Garets, & Handler, 2003; Hasman, Safran, & Takeda, 2003). An “information inequity” has also been suggested, where those with the most severe health problems are often those with the weakest health information systems (Stansfield, 2007). In developing countries, the problems of health information are exacerbated due to: the absence of standards and identifiers; medical

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