Chapter 43

Australian Patient Organizations:

Using Digital Technologies to Engage Health Citizen Communities in Health Policy

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ABSTRACT

Three citizen health organizations in Australia are examined for how they are consuming information and communication technologies. In particular, how they are actively domesticating and taming the internet as part of their everyday practices and how this is transforming participation, citizenship, and civil society in the health sector are explored. The organizations, Diabetes ACT, Health Care Consumers' Association of the ACT, and AIDS Action Council of the ACT are all located in Canberra in the Australian Capital Territory (ACT). The chapter focuses on how each organization imagines and configures their communities and how this leads to differences in their ways of interacting with the internet.

INTRODUCTION

The last three decades have seen a growing role for patient organizations in the production of health policies and services. These citizen health organizations are increasingly engaging with healthcare professionals and government decision-makers in the health policy arena in order to advance the interests of their constituencies. Changes in terminology from patient self-help group to health-care consumer organization to citizen health organizations abound, reflecting differences between missions, countries and also in the time-period during which the organization was established (Brown, Zavestoski, McCormick, Mayer, Morello-Frosch, & Altman, 2006; Callon & Rabeharisoa, 2008; Epstein, 2007). In this chapter

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the term citizen health organization is preferred and applied generally to describe any organization of patients, users or civil society; although it warrants attention it is beyond the scope of this chapter to take up debates about who counts as a citizen or is entitled to state funded health care (Tyler, 2010), the term citizen here is interpreted inclusively to mean residents or inhabitants. The organizations discussed here can be characterized as made up of people who are not health professionals or certified experts but ordinary people who are concerned with health care, often because of their experience with diseases and health conditions. The increase by lay people in health policy and service design has occurred simultaneously with Government Departments and Ministries of Health looking to the active participation of users of health services, and calling on them to contribute their knowledge to the better governance of health. This chapter looks at three different models for organizing citizen participation in health care adopted by patient organizations in Australia's capital city of Canberra. Of particular interest is how Information and Communication Technologies (ICT) are facilitating and enabling such engagement.

BACKGROUND

Information and communication technologies (ICT) and the internet particularly continue to be portrayed as radically transformative of civil society. The qualities of the internet, its decentralized and distributed character, and the ease and speed with which information can be distributed have been seen by many as forces to strengthen civil society and the participation of citizens in the design of government policies and services (Chadwick & Howard, 2008; Gibson, 2009; Williamson, 2009). ICT have been hailed as democratizing the relationship between health care systems and their consumers. More informed patients it is said will participate as equals in their individual treatment decision-making, and in the transformation of health policies and services (Wathen, Wyatt & Harris, 2008). It has become commonplace in science and technology studies or science, technology and society (STS), to critique such technological determinist arguments that proceed from the characteristics of a technology to social and behavioral change, assuming that the technology itself will drive change (MacKenzie & Wajcman, 1999). This chapter starts from the assumption that there are no *a priori* boundaries between the technical and the social, between technoscience on the one hand and politics on the other, providing neat categories that can be studied as a simple linear matter of the impact of a technology on society (Asdal, Brenna & Moser, 2007). These are conceptual boundaries of our making, found in our imagination, and as researchers we have as Latour suggests (Latour, 1987) followed the actors and their categories. Accordingly, this chapter sets out to show the entanglement in everyday, real-life, empirical situations of human and non-human actors, material and symbolic practices and resources, values and machines. To do otherwise is to dodge our responsibilities as researchers.

The chapter is based on research commenced at the end of 2007 and continuing with interviews through 2008 and beyond that through ongoing website observation to investigate the "consumption" of ICT in third-sector, not-for-profit citizen health organizations. This research project set out to explore how ICT are transforming participation, citizenship, civil society and democracy in the health sector. It investigated the contradictions and complexities faced by contrasting citizen health organizations in Canberra, Australia's capital city located in the Australian Capital Territory (ACT), as they grapple with increasingly ICT mediated participatory processes with governments and health service providers, at the same time utilizing ICT to build and empower their constituencies to intervene in the production of health services and health policy.

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