

Comment on: “Moving from Patient Advocacy to Partnership: A Long and Bumpy Road”

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Wong-Rieger rightly pledged for a transition from patient advocacy to partnership but her theoretical framework with four schematically psychosocial personalities overlooked the real-life issues [1].

First, partnership is already present. Two thirds of patient advocacy organizations received industry funding [2]. Greater transparency by the addition of patient advocacy groups to the Open Payments program (Sunshine Act) would be a flawed compromise: disclosing conflicts cannot dissolve them. A charity should not be registered among patient organizations if it accepts external funding, as healthcare professionals for a task force should not. Could a spoon be long enough to soup with the biggest defrauder ever? [3]. Industry’s first goal is and will always be to create value for its shareholders.

Second, believing decision makers, including government agencies, could look for partnership with genuinely “independent patient and citizen voices” must not overlook the fact that cost constraints or economic issues are major issues for them. Third, partnership cannot be one-sided. The ignorant who are “motivated by good intentions” can be so easily fooled. Patients’ advocates must develop basic skills about medicine (e.g., public health, pharmacology, psychology, clinical trials methodology) but also about strategic planning and communication. AIDS activists developed such skills, better than many professionals, and produced new paradigms, which is why they succeeded [4].

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Sadly, major steps forward, as by AIDS activists, are too few and must not mask potential drawbacks. Public outcry can unduly preclude the use of safe alternatives [5]. The pink ribbon campaign for breast cancer screening used public fervor to transform a disease into a market-driven industry, which is deliberately flying in the face of the scientific evidence challenging the clinical benefit of screening [6].

Advocacy for patients is not a gift from heaven, it needs not only efforts but also wisdom.

Compliance with Ethical Standards

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