The Politics of Self-Craft: Expert Patients and the Public Health Management of Chronic Disease

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Abstract

As the global challenges posed by chronic, noncommunicable diseases (NCDs) run into longer life expectancies and restrictive fiscal environments, public health programs must respond to these issues. In doing so, health practitioners have framed NCDs as apolitical and largely the product of an individual’s risk behavior. Consequently, governance strategies embraced by public health to address NCDs emphasize the role of the private sector, including opportunities for patient self-management of illness. The Expert Patients Programme (EPP), an initiative of the U.K. Department of Health, applies to a range of chronic conditions. Via a case analysis of the EPP, this article argues that public health governance of NCDs is increasingly a project of individuals’ self-governance, and that although the techniques of the EPP are constructed as politically neutral, they rather demonstrate a pervasive neoliberal political rationality: in devolving public health responsibilities to the private sector and in constructing the healthy, active participant whose primary aim is to return to an economically productive life.

Keywords

noncommunicable disease, governmentality, public health governance

Overview

In the realm of global health governance, it seems that noncommunicable disease (NCD) is a subject whose time has come. On the heels of the World Health Organization’s (WHO) 2009 action plan on the global prevention and control of NCD, in September 2011 the United Nations General Assembly held its first high-level meeting on the growing burden of chronic NCDs worldwide. Such phenomena indicate a growing awareness not only of the severity of the challenge posed by NCDs but also of the need to develop a more coordinated governance response.

That NCDs—especially heart disease, cancer, diabetes, and chronic respiratory illness—are a preeminent global health issue is well documented; these four conditions alone account for 60% of global mortality annually, with 80% of those deaths occurring in middle- and low-income countries. Moreover, NCD mortality is expected to increase by 17% over the next decade, with the greatest increase occurring in the African region (WHO, 2009).

As the burden of NCDs expands globally and public health systems must address them in an increasingly tight fiscal environment, the question emerges, “How has public health evolved to address these challenges?” and “What are the political implications of this evolution?” In answering these questions, we must attend to the discursive norms by which public health as a discipline constructs “truth,” “fact,” and “knowledge,” and the programs and policies whose very bones are that truth that the discipline invokes. In other words, we must engage with the explanatory models that are privileged and the public health policies that are built on them.

The discursive norm for public health research frames degenerative NCDs as largely apolitical; they are typically construed as the product of an individual’s risk behavior—particularly in the form of tobacco usage, sedentary lifestyle, and poor diet. So too has their solution primarily been understood as existing in the individual body and the choices one makes.

This depoliticization is complemented by the frequent characterization of public health, and especially epidemiology, as engaged in neutral science. As Savitz, Poole, and Miller (1999) note, Epidemiologic research derives from theory and uses rigorous methods to yield results that should be described as objectively as possible. Investigators should strive to interpret accurately, and when biases intrude, their colleagues should help with constructive criticism. (p. 1158)
An approach that frames the sources of chronic disease in the behavioral choices of individuals and also casts that knowledge in the language of objective science effectively treats such illnesses as apolitical phenomena. However, a close examination of the practices of public health, particularly those oriented toward the management of chronic NCDs, reveals a pervasive underlying political rationality that complicates the discipline’s claimed objectivist view. Specifically drawing on the Foucauldian notion of governmentality or “government rationality,” this analysis answers the aforementioned questions in the following way. First, it argues that the public health has responded to the challenge of NCDs in such a way that it is losing its claim to being truly “public”—by focusing more on individual bodies than population and also by increasingly adopting the accoutrements of the private sector. Second, it argues that these features are neither random nor coincidental but instead reflect a dominant underlying neoliberal political ideology. This argument is developed and substantiated here through a close and detailed examination of one such broad-based approach to NCD management: Britain’s Expert Patients Programme (EPP), a comprehensive strategy first broached in 1999 to deal with the rising burdens posed by NCDs such as cardiovascular disease, cancer, diabetes, and mental illness.

**Neoliberal Governmentality and Public Health**

Before elaborating more explicitly how this is the case, a few preliminary clarifications are in order. The first pertains to the concept of “governmentality.” Generally, it may be understood as any more or less calculated and rational activity, undertaken by a multiplicity of authorities and agencies, employing a variety of techniques and forms of knowledge, that seeks to shape conduct by working through our desires, aspirations, interests and beliefs, for definite but shifting ends and with a diverse set of relatively unpredictable consequences, effects, and outcomes. (Dean, 1999, p. 11)

Governmentality, then, is a rationality of government that is decoupled from the exclusive province of the state but rather is directed more broadly toward the “conduct of conduct,” or the deliberate molding of private behavior in accordance with specific norms and toward specific ends (Dean, 1999; Foucault, 1982; Foucault, 1991; Gordon, 1991). In so doing, it operates through three interrelated spheres: episteme (systems of knowledge and expertise), techne (the technologies of power and rule), and ethos (the privileging and cultivation of a particular kind of ethical subject; Dean, 1999; Foucault, 1991; Rose & Miller, 1992).

Having established the general framework of governmentality and its three interrelated spheres, it is important to clarify what is meant by neoliberalism—which reflects a particular style of governmentality. Although the term is commonly understood to entail particular modes of economic practice—free trade, deregulation, privatization, and the like—it is not only simply reducible to a set of policy prescriptions but may also be understood more broadly as a style of governance that in turn guides such actions in the economy and other spheres. Unlike earlier incarnations such as classic liberalism, in which the market is understood as a separate and distinct sphere, neoliberal government is a unique reformulation that involves the extension of market logic and values to all spheres:

To be sure, the point of doing this is to prevent excessive government by ensuring the most efficient use of resources. But it is also, and perhaps more importantly, to reform institutional and individual conduct so they both come to embody the values and orientations of the market, expressed in notions of the enterprise and the consumer. (Dean, 1999, p. 172, emphasis added)

In this regard, the neoliberal impulse not only involves attempts to reinvigorate classic liberal principles pertaining to cost and operational efficiency and a limited role for the state—as evidenced in particular policies of privatization, decentralization, and deregulation—but also extends them to new spheres, such as the family, the school, and the clinic (Dean, 1999). For these principles to operate effectively in such spheres, several assumptions are made that speak not only to the centrality of the individual actor under this political rationality but also to three additional features of neoliberalism. These are as follows: (a) Choice is the key human faculty “that overrides all social determinations”; (b) the rational individual making these choices can be educated to make the “appropriate” ones, insofar as “modifications in behavior follow from remodeling the environment according to this market rationality”; and (c) the individual approaches himself or herself as an entrepreneur, as human capital, in an endeavor “to obtain both monetary earnings and psychic and cultural satisfactions” (Dean, 1999, p. 57).

From this brief sketch, we can ascertain the basic orientation of neoliberal government; it is one that seeks “to extend the rationality of the market, the schemes of analysis it proposes, and the decision-making criteria it suggests to areas that are not exclusively or not primarily economic” (Foucault, 1997, p. 79). In the case of public health, we witness the operation of a neoliberal governmentality in the extension of market logic to various dimensions of the health experience: the construction and production of individual, rational participants whose decisions regarding behavioral modification are predicated on cost-benefit analysis; the production of knowledge in accordance with theoretical models that assume such a subjectivity and, as such, focus primarily on behavioral predictors of health outcomes; and the promotion of health strategies, targeted at individuals, that have been
directed toward the cultivation of self-governing participants who take an entrepreneurial approach to the management of their health and well-being.

This intimate connection between public health and a neoliberal governmentality is tangible, and has been part of the critical public health discourse for quite some time, as evidenced by the work of a number of scholars, including O’Malley (1992), Petersen and Lupton (1996), Joyce (2001), and Thanem (2009). Health promotion especially has been singled out as an area reflecting a particularly neoliberal political rationality:

The endeavours of health promotion are easily recognizable as the strategies of liberal governmentality. That is, they are directed at the level of the population, they constitute individuals and groups as “problems” and domains of governance needing the assistance of health promotion “experts,” they are systematic, calculated and directed at defined ends, they emerge from the state but are also articulated by associated independent institutions and agencies. (Lupton, 1995, p. 49)

Moreover, elements of a governmentality approach have been applied to a number of arenas of health and human welfare, including obesity and the use of the body mass index (Evans & Colls, 2009), HIV/AIDS education (Schee & Baez, 2009), learning disabilities (Gilbert, Cochrane, & Greenwell, 2005), nursing (Clinton & Hazelton, 2002; Holmes & Gastaldo, 2002; Winch, Creedy, & Chaboyer, 2002), hormone replacement therapy (Harding, 1998), mental health and psychiatry (McCallum, 1998; Tyler, 1998), and eating disorders (Eckermann, 1998).

The appropriateness of such an approach for medical and health issues is indicated by their concern with the well-being of bodies and minds—a domain that necessitates government to achieve the ends of health and happiness. Dean (2002) notes that

[T]he analytics of government, conceived as the multidimensional analysis of the different ways in which our conduct is guided and directed, and for various ends, exists within a broader field . . . This field includes the powers of death, of punishment and of coercion . . . [and] also includes the powers of life, of the living, and of the processes of life, which have previously been assigned the title of “biopolitics.” (p. 123)

If governmentality is therefore concerned with the government of life, those domains that are especially devoted to its enhancement, regulation, and preservation—such as public health—are particularly amenable to a critical interrogation within a governmentality framework. The application of such a framework to the specific realm of public health is most notably evident in the work of Petersen and Lupton (1996), whose critical analysis of the field looks particularly at the implications of health knowledge and practices for the development of self-identity and notions of citizenship. The individual work of Lupton (1995), as well, has also emphasized the exercise of disciplinary power in the discourse and practice of public health, with particular attention to the application of Foucauldian notions of subjectivity to the construction of “healthy” citizens.

In the context of minimizing the burdens posed by NCDs, contemporary public health employs technologies such as health promotion that are intimately linked with the realm of subjectivity. Predicated on theories of health behavior that assume a rational, calculating participant and directed toward the production of an entrepreneurial self actively engaged in maintaining his or her own health, public health education and promotion campaigns privilege a particularly neoliberal participant. Kelly (2001) notes in this regard that “(Neoliberal governmentality . . . attempts to reconfigure the practices of government by conceiving the subject as rational, autonomous, choice making and responsible” (p. 29). Thanem (2009) expands on this construct by emphasizing that under neoliberal governmentality, that self-management is intrinsically engaged in the ethic project of promoting individual freedom.

It is the analysis of this latter dimension of neoliberal government in public health, the cultivation of the entrepreneurial and self-governing subject, which is the substance of the rest of this analysis. The entrepreneurial subject has a privileged place in many areas of public health practice, especially those pertaining to chronic, NCDs such as cancer, heart disease, and diabetes where lifestyle plays such a critical role in prevention and management strategies. More specifically, as the challenges posed by long-term debilitating conditions run headlong into longer life expectancies for most in the industrialized world, many public health programs are seeking to enhance opportunities for patient self-management of these conditions.

One such program, the EPP, began as an initiative of Britain’s Department of Health to help patients increase their confidence, improve their quality of life, and better manage their condition. Designed to apply to a wide range of conditions, including cancer, diabetes, heart disease, chronic pain, and other conditions, it has become an important component of the contemporary British public health system. Although the techniques and strategies of the program are constructed in such a way as to seem value free and politically neutral, a close reading of these techniques demonstrates a pervasive neoliberal political rationality underlying them, particularly as they pertain to the construction of the healthy, active, and engaged participant.

Before delving into the particulars of the program itself, it is worth clarifying why the EPP merits such close examination. The first reason is that it is a national campaign and therefore broad in scope; in practical terms, public health activities are often enacted in very decentralized settings, and there may not be cohesion as to the content or direction across different locales. This feature does not entirely
programs that are central to that project. As such, one is able to speak of a public health initiative as something more than a district campaign that is completely unique and particular, and not necessarily applicable elsewhere.

Second, and this aspect will be illustrated more fully and in greater detail in the case discussion, is that Expert Patients is targeted toward the entirety of the population experiencing chronic disease. If we are to examine how public health is implicated in the construction of healthy participants, it stands to reason that the campaign should either be universal in scope—so that no one is excluded—or directed toward those who are most at risk, and thus have the most to gain from a transformation in how they relate to and manage themselves.

Last, as the 2010 White Paper on the state of British public health indicates, the system described above stands at a crossroads and faces a reorientation in how the aims of public health are accomplished—namely, a proposed further move toward localization and limiting the role of a centralized public health system to act as facilitator of “good choices” (Secretary of State for Health, 2010, p. 23). Thus, to the extent that the public health system in Britain moves deeper into the decentralization and emphasis on personal responsibilities that are the sine qua non of neoliberalism, the more important it is to understand and interrogate those programs that are central to that project.

**Expert Patients and the Management of Chronic Disease**

In 1999, the British government established a task force to develop a new approach to managing the public health challenge posed by chronic NCDs, known as the Expert Patients Programme; the logic behind its development centered on several observations made by those in the health community—clinical and public health. The first is that for those individuals living with chronic diseases such as diabetes, health professionals had for some time noted that “my patient understands their disease better than I do”; complementing this perspective was one that acknowledged that the understanding and experience gained by patients were a resource yet to be fully embraced by those professionals guiding their care. Finally, the government acknowledged that the emphasis on practical care in North America and elsewhere was coming to place more responsibility on the shoulders of those living with chronic disease (The Expert Patients Task Force, 2001). The Expert Patients proposal asserts,

> [T]oday’s patients with chronic diseases need not be mere recipients of care. They can become key decision-makers in the treatment process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. (The Expert Patients Task Force, 2001, p. 5)

The logic behind this initiative is not predicated on traditional models of health education—where at-risk individuals or patients are given information about their condition and associated risk factors, and tools and techniques for maximizing health. Rather, the activities associated with Expert Patients are very much targeted at not only managing illness but also evolving a subjectivity of empowerment necessary to that successful management:

Patient self-management programmes . . . are based on developing the confidence and motivation of patients to use their own skills and knowledge to take effective control over life with a chronic illness. (The Expert Patients Task Force, 2001, p. 6)

In the context of its development as a national public health strategy for managing NCDs and other chronic illnesses, the EPP was the evolution of a number of prior existing chronic disease self-management programs (CDSPs) in the United Kingdom. These programs, covering such illnesses as arthritis, multiple sclerosis, and mental illness, among others, were all developed by patient groups and/or advocacy organizations, and covered a range of issues for participants, from exercise and nutrition, symptom recognition and management, and communicating with health care professionals (The Expert Patients Task Force, 2001).

The decision to move forward with a more cohesive and broad-based approach to CDSPs in the form of Expert Patients was informed by several factors. First was a review of these and other CDSPs for their efficacy. Barlow, Turner, and Wright (2000), in their review of CDSPs, found that self-management programs were consistently associated with several positive outcomes, regardless of illness. These included a reduction in the severity of symptoms, a significant decrease in pain, improved activity levels, and greater life satisfaction (Barlow et al., 2000). When assessing the impact of these programs on service use—such as general practitioner (GP) consults or emergency room visits—evidence has also pointed to the efficacy of these programs. For example, for general chronic pain conditions as well as specific diseases such as arthritis, health professional consults were reduced by up to 80% (Barlow, Williams, & Wright, 1999; Cole, 1998).

In addition, studies charting the effects of self-management programs on service use by asthma patients reveal a reduction in GP consults by up to 44% (Charlton, Charlton, Broomfield, & Mullee, 1990) and a reduction in emergency room visits by 39% (Choy et al., 1999).

A second factor was the number of people estimated who could be helped by making self-management programs a
systematic feature of chronic disease management techniques of the National Health Service (NHS). At the time of the Expert Patients proposal in 2001, approximately 17.5 million Britons were living with chronic diseases, the majority of them NCDs; the Department of Health Task Force estimated that with the EPP in full effect, approximately 14.4 million could experience tangible benefits (The Expert Patients Task Force, 2001). The specific benefits, and the ways and degrees to which they would be achieved, were assumed to be variable across illnesses and across patients—largely due to the variable nature of the illnesses themselves, the management issues they raise, and the attitudes of patients (The Expert Patients Task Force, 2001).

As laid out by the Expert Patients report, the program would evolve in two stages. The first was a pilot phase between 2002 and 2004 that monitored and evaluated programs pursued by local health authorities; the second phase of implementation, occurring between 2004 and 2007, began systematizing the programs throughout the NHS (The Expert Patients Task Force, 2001). In 2007, the program was further systematized with the establishment of the EPP Community Interest Company (CIC), which would work to expand the reach of self-management courses throughout the system. The EPP CIC was charged with expanding the number of course places per year from 12,000 in 2006 to 100,000 by 2012; in so doing, the mission of the company has been to “establish the principle of individual self-management and self care as a recognized public health measure, deliverable in a cost effective and sustained way” (EPP CIC, 2011a). Two general points are relevant here: first, the devolution of primary responsibility for the EPP from the NHS to a private-sector entity and second, a mission statement that, perhaps unsurprisingly, expresses an explicit market logic for the EPP, which would evolve in two stages. The first was a pilot phase between 2002 and 2004 that monitored and evaluated programs pursued by local health authorities; the second phase of implementation, occurring between 2004 and 2007, began systematizing the programs throughout the NHS (The Expert Patients Task Force, 2001). In 2007, the program was further systematized with the establishment of the EPP Community Interest Company (CIC), which would work to expand the reach of self-management courses throughout the system. The EPP CIC was charged with expanding the number of course places per year from 12,000 in 2006 to 100,000 by 2012; in so doing, the mission of the company has been to “establish the principle of individual self-management and self care as a recognized public health measure, deliverable in a cost effective and sustained way” (EPP CIC, 2011a).

This push to expand, in the systematization phase and under EPP CIC, has been successful; according to the National Primary Care Research and Development Centre—United Kingdom (2004), 62 primary care trusts (PCTs) were targeted for participation in the EPP. Since the establishment of the EPP CIC, that number has expanded to include nearly half of all PCTs in England, as well as local health boards in Wales and Scotland (EPP CIC, 2010). In addition, more than 50,000 people have participated in an Expert Patients course (although this is a very small number relative to the estimate of 14.4 million who could be helped by EPP as laid out in the Task Force Report; EPP CIC, 2011a).

During its development, EPP emphasized eight programmatic elements, covering issues ranging from NHS-created programs, to improving partnerships with patient organizations, to the training of health care professionals. These include the promotion of awareness of the critical role of the patient in managing chronic disease, the establishment of new user-led self-management courses designed to help patients develop skills to manage their illness, the identification of barriers to mainstreaming self-management programs in the NHS and the development of solutions to these barriers, greater integration of existing user-led programs into the current NHS framework, assurance that PCTs either have or will establish self-management programs for specific conditions, expansion of financial and other support for patient organizations pursuing their own self-management courses, incorporation of health care curricula coursework highlighting the benefits of “Expert Patients” programs to health professionals, and the establishment of a national coordinating and training resource to assist health professionals in keeping abreast of theoretical and practical developments in the evolution of self-management programs (The Expert Patients Task Force, 2001).

The Work of Expert Patients

Given these broad goals, it is helpful to clarify exactly what the content of self-management courses executed under the auspices of the program includes. The CDSPs in the British context are based on the original chronic disease self-management course developed by Kate Lorig at the Stanford Patient Research Education Center. Whether focused on arthritis, heart disease, cancer, or other conditions, there is a standard format. Participants attend six weekly sessions, each lasting 2.5 hr; the size of the class ranges from 8 to 16 patients, with the idea that small groups facilitate greater interaction and contact with tutors. Two tutors—themselves chronic disease patients and often former participants in the program—lead each session, and cover topics in a self-management manual such as diet, exercise, and symptom recognition and management. Although this dimension speaks to an educational impulse, the primary goal is to enhance “self-management skills” that will better enable the patient to care for himself or herself (Long-Term Medical Conditions Alliance, 2001).

By enabling the individual to recognize an innate ability and desire to manage the challenges that impede better health, Expert Patients is geared toward the enhancement of self-government. To the extent that these challenges, or the substance of the ethical work to be undertaken, are constructed as “risk,” we witness a complex manifestation that covers the breadth of life experience and extends well beyond the potentiality of disease that the notion of risk conveys. In other words, risk management is certainly a major feature of Expert Patients, hence the multiple weeks spent on strategies to improve diet and increase exercise, or sessions spent on relaxation techniques to reduce stress. But unlike other NCD programs, which are distinctly preventative in their orientation, Expert Patients is directed toward the management of illness already manifest—risk exploded beyond the realm of probability into the tangible experience of cancer, arthritis, cardiovascular disease, or many other conditions.

Hence, the ethical substance of Expert Patients constitutes the management of risk, yes—for it is omnipresent, and a person with a chronic disease such as asthma may yet
fall prey to another like cancer. However, the obstacles to health under this program also include the effects and travails that one confronts when already living with a NCD: issues pertaining to treatment, medication, as well as emotional components such as anger, frustration, or fear. These dimensions, therefore, are part and parcel of Expert Patients self-management courses, and of training people to govern their own health, in a way that they are not in other chronic disease programs oriented toward prevention.

In addition to the educational component, another important element is that of the “action plan” or “contract.” Toward the end of each session, tutors initiate this component by describing the contract they are making with themselves for the following week (Long-Term Medical Conditions Alliance, 2001). These contracts involve specific goals, often pertaining to the specific content covered for that week—such as getting some form of activity 3 times a week or implementing strategies to manage fatigue. At that point, participants develop and share publicly their own action plans for the following week, and review their progress or success in fulfilling their contract the previous week. One of the major reasons that the course extends over a 6-week period is the importance of this dimension: “Sessions are spaced to enable participants to practice new skills, do their reading assignments, reflect on the last session and crucially carry out their ‘contracts’” (Long-Term Medical Conditions Alliance, 2001, p. 2, emphasis added).

Two points are especially relevant here. The first, and perhaps most obvious, dimension of the infiltration of economic logic to the execution of public health programs such as Expert Patients is the explicit application of contractualism to the program content. Participants in this regard are brought to view and manage their lifestyle in such a way as to mimic the relations between agents in a market environment—the fulfillment of obligation for the generative end; in this case, not of wealth but rather of health and well-being. A second point pertaining the role of the contract with the self as a vehicle for ethical work concerns the role of voluntary surveillance. To assess, whether in weekly public meetings or in the private space of the home on a daily basis, whether the contract is being fulfilled, the expert patient necessarily engages in an ongoing basis on the self-surveillance of his or her habits, choices, concerns, worries, and successes.

The self-management course illustrates the domain of this surveillance activity in the content that it covers: not only aforementioned issues of diet, activity, and symptom management but also activities pertaining to relaxation; managing fatigue; use of medications; communication with family, friends, and coworkers; communication with health workers; making treatment decisions; developing future plans; improving problem solving; and managing anger, fear, and depression (Long-Term Medical Conditions Alliance, 2001).

Thus, the domain of life is the domain monitored, and although for a finite time the self-monitoring is reinforced by the commitment to share its results in a public setting, the aim of the program is to engender this attitude well beyond the last meeting. Moreover, it should be emphasized that the context of the public dimension of this surveillance activity is not akin to the expert gaze directed at the patient in a clinical setting. Rather, the environment fosters a sense of community-in-laiity status—even as the program cultivates the expertise of that laity: “[T]hese feed-back sessions are exciting, funny, and almost always moving as people rediscover their potential” (Long-Term Medical Conditions Alliance, 2001, p. 2).

The privileging of the individual so consonant with neoliberalism is a key element of the EPP. As stressed before, key components of this privileging include an emphasis on the development of one’s autonomy and sense of capability. According to the Department of Health Task Force, one of the key aims of the program is to develop [U]ser-led self-management courses to allow people with chronic diseases to have access to opportunities to develop the confidence, knowledge and skills to manage their conditions better, and thereby gain a greater measure of control and independence to enhance their quality of life. (The Expert Patients Task Force, 2001, p. 34)

By developing programs in such a way as to emphasize the generative effects of risk and disease management—a fuller, more healthy life, greater self-esteem, enhanced abilities, and the like—Expert Patients does not need to engage in project of coercion to good health. Rather, it is structured in such a way as to facilitate in the potential participant the desire to govern his or her health.

Here, we witness in practice how the individual is induced to cultivate an entrepreneurial, healthy subjectivity, as the expert patient is motivated to undertake the ethical work of self-craft by the ultimate rewards that the cultivation of self promises. Although the engagement in risk monitoring and management is indeed predicated on the degree of will, desire, and follow-through of the expert patient, one must not assume that this motivation originates in the internal, sui generis; it is cultivated in part by the deployment of certain practices designed to recruit participants in the first place. The first major evaluation of the pilot phase of Expert Patients, published in 2004, identifies that a number of advertising strategies have been pursued to bring target patients into the fold: mailbox leaflets; posters at grocery stores, libraries, and pharmacies; advertising in local newspapers or other circulars; and many others (National Primary Care Research and Development Centre–United Kingdom, 2004). To raise awareness and more importantly interest, Expert Patients communicates the benefits of participating—as outlined above. In this regard, the mode of subjection to engage the ethical work does not originate internally but is the product of marketing, whose success depends on the
internalization of the message by the “consumer”—such that
they come to view it as generating from their own interests,
desires, or needs.

Reinforcing the subtlety of this maneuver is the fact that
the most heavily pursued recruitment strategy by PCTs
involved in Expert Patients was the sending of leaflets and
flyers to individuals, medical practices, and other organiza-
tions; such a method increases the likelihood of self-referral,
as opposed to other methods such as direct intervention,
lectures, or “awareness days.” As a result,

this fits with the ethos of self-referral which is stressed
as an important component of some self-management
programmes. (National Primary Care Research and
Development Centre–United Kingdom, 2004, p. 14)3

The effect of this advertising practice—and its intended
consequence of generating self-referral—is to highlight once
again the primacy of the individual, of cultivating individual
motivation in the pursuit of self-efficacy. These principles
are affirmed by Tony Burgess, of the West Norfolk PCT, who
characterizes the program in this manner:

The Expert Patient Programme started with the premise
of addressing a patient with problem, not of
addressing an example of a disease process. So it’s
talking about an individual having a problem and how
they deal with it. Saying to the individual, “you are a
patient with arthritis, or diabetes, or cancer, or CHD:
not a diabetic like every other.” (National Primary and
Care Trust Development Programme, 2003, pp. 7-8)

While a major component of the EPP has been to empha-
size the worth of the individuals in their illness experience,
and to guide them toward a subjectivity of empowerment in
the way they relate to their bodies and the diseases that affect
them, a concomitant aspect of the program is geared toward
the empowerment of the individual in how they relate to
health care professionals. Rather than a hierarchical system
predicated on division of expert knowledge and lay experi-
ence, the EPP is geared toward the transformation of the
patient’s subject position to one of equality. This is stressed
by health professionals involved in the EPP as well as par-
ticipants. Hilary Daniels, chief executive of the West Norfolk
PCT, thus views an expert patient as “someone who is able
or enabled to have a conversation with their clinician(s) as an
equal partner in their care” (National Primary and Care Trust
Development Programme, 2003, p. 4). This is echoed by
Nicola Jones, a GP who first became involved with the EPP
in 2002. In her experience,

They have the confidence to manage their condition.
They demonstrate resourcefulness, not asking “what
should I do?” but rather “do you think this will work?”
It’s about control. People with chronic conditions get

that back. It is a thing you take for granted until you
have lost it. (Jones, 2003)

Such a perspective is echoed by participants in the pro-
gram, one of whom characterizes the transformation of self in
such a way as to emphasize empowerment and confidence in
the patient/clinician relationship:

I now see him [the GP] as more of an equal whom I
can refer to, rather than a God whom I can’t approach.
I feel I have more of a right to be there talking to him,
and that it’s more of a partnership than anything else.
(National Primary and Care Trust Development
Programme, 2003, p. 23)

That sense of empowerment in the doctor–patient rela-
tionship is echoed by Norman Johnson, an expert patient
who is now training to be a tutor for new participants:

It’s about gaining self-confidence and taking control.
Those who have completed it are more confident with
being able to go up to a health professional and be able
to talk to them more. It brings people out of themselves
more. (National Primary and Care Trust Development
Programme, 2003, p. 25)

As we have witnessed, Expert Patients operates toward
the end of cultivating the empowered, autonomous self—
two features consonant with neoliberal rationality; yet
another aspect of subjectivity highlighted by the EPP is the
emphasis on self-management for the purpose of leading a
more productive life. In this sense, “productive” refers not
only to the ability to do day-to-day activities such as house-
work or hobbies but also with regard to employment. Siobhan
Long, a participant in an Expert Patients pilot program for
chronic pain, describes the contribution the program has
made to her goals of financial independence and economic
gain:

The main thing is that it gave me encouragement to
still have goals in life, but to break them down into
more manageable pieces and accept that reaching
them may take time. For me personally, I am hoping
to get back into paid work, as I want to be able to
regain the economic independence that I used to have.
(National Primary and Care Trust Development
Programme, 2003, p. 21)

That participants such as Siobhan would evolve this or-
ientation toward the project is perhaps not surprising, given
that economic productivity is one of the aims of Expert
Patients cited by the Department of Health. In its stated
vision for a successful program, the department asserts that
Expert Patients should ultimately enable “many people with
chronic disease [to] gain and retain employment” and help
“people with chronic disease make greater use of Adult Education and employment training programmes” (The Expert Patients Task Force, 2001, p. 14).

A second dimension through which Expert Patients facilitates the construction of the productive self is via the privileged role it grants to its tutors and trainers, who are often themselves “graduates” or former participants of the program. By contributing—often in a volunteer capacity—their time, counseling, and experience, they aid in the growth and expansion of the CDSP model. For example, the Heart manual, a program in use in Britain for management of cardiovascular disease risk, grew to include more than 4,000 trainers, who now reach approximately 18,000 patients every year (NHS-United Kingdom). The expansion of this particular model of self-management training is informed by the fact that all tutors, having gone through training, do not have subjective control over the content of the Expert Patients courses; rather, the CDSP “is delivered from a rigorously followed script, so all participants experience the same course content, regardless of who is leading it” (Long-Term Medical Conditions Alliance, 2001, p. 1). Thus, the production of new tutors facilitates the reproduction of the consumable good: in this case, a health promotion program designed to empower patients to manage their lives and health better.

Related to the expansion of self-management programs under the auspices of Expert Patients is a corollary dimension of cultivating the productive self; that is, the productive self also emerges as a consequence of tutors’ facilitating the development of new Expert Patients. Insofar as they assist new participants in taking control of their lives, they facilitate the expansion of self-government. The impulse for these actions is often informed by a desire to contribute something in return for the value they feel they have gotten out of the program. The Expert Patients pilot phase report evaluates the motivations for former participants to undergo training as tutors: “Many tutors saw becoming involved in EPP as a chance to be reciprocal—to give something back as a result of regaining a focus to their lives” (National Primary and Care Trust Development Programme, 2003, pp. 25-26). This dimension of giving back, of making a positive contribution to the further development of the program, also ties the practice of the reproduction of Expert Patients to the citizenship impulse described by Petersen and Lupton (1996). The good citizen invests in self as a means to achieve well-being and to unburden the state in its responsibility to secure his or her health. Tutors, however, in not only managing their lives and diseases responsibly, but also by helping to facilitate the development of new expert patients capable of promulgating the program, manifest in a neoliberal context an especially ethical relation not only to self but also to society.

This promulgation has been a cornerstone of the EPP, and via the techniques of decentralization and the responsibilization of the individual, further obscures the nuanced and multilayered determinants of health-related choices. Social epidemiologists such as Marmot (2004, 2005) thoughtfully demonstrate how disease outcomes (and by implication our individual choices that lead to these outcomes) are structured by socioeconomic factors; yet issues of access and inequality have not been central themes in this particular program. Of course, there is awareness that issues of poverty or health inequity are relevant. For example, EPP Representative Peter Johnson states, “Our aim is to reduce inequality and achieve better health outcomes nationally and locally, by increasing the capacity of our volunteer force.” What is noteworthy here is that while inequalities or resource issues that contribute to poor choices are deemed an issue, the means by which they are addressed are not via redistribution or other directly targeted means of the EPP. Rather, it is via the expansion of a private sector, volunteer-based force that is inherently consistent with neoliberalism that this is to be achieved.

There is one other avenue by which we can evaluate the EPP’s relative lack of emphasis on this issue. In many respects, it is taking its cues from the larger organizational structure in which it has historically been embedded. While the Department of Health and the NHS have emphasized addressing quality of service delivery to patients with chronic conditions, their definition of a positive patient experience is one of “having information to make choices, to feel confident and feel in control; being talked to and listened to as an equal; and being treated with honesty, respect and dignity” (EPP CIC, 2011b). Thus, the framing focuses on empowerment and informational access, as opposed to underlying structural resource issues that might be conditioning poor choices.

Through all of these dimensions of the EPP—the responsibilization of the individual, an emphasis on autonomy and empowerment, the development and hence investment in one’s health and life through the acquisition of new knowledge and skills, and the emergence of a productive and ethical self—we are able to encounter how this health promotion program is implicated in the production not only of health but also of a dominantly neoliberal subjectivity. There is no doubt that the construction of Expert Patients is simultaneously an exercise in the construction of participants.

The NHS captured this notion in a promotional tagline for the EPP that was subsequently employed by several PCTs: “Moving from patient to person.” Such a catch phrase is revealing in that the governing institution responsible for the deployment of this public health strategy frames it in such a way that the process of developing the skills and abilities of an expert patient is really an exercise in acquiring personhood or subjectivity. Thus, Wilson concludes that with regard to the EPP, “there has been a move away from the objectifying of patients, to the subjectification of patients where they are looked at holistically by practitioners” (Wilson, 2001, pp. 138-139).

More importantly, perhaps, the subjectification of patients is not so much the views that are engendered between practitioners and patients (although these are indeed relevant) but rather the ones that the patient—participant—engenders
toward himself or herself. More specifically, Expert Patients speaks not only to the rehabilitation of one’s body or life regimen but also of the relationship to the self. The process of acquiring an ethical relation toward the self—one predicated on good health, empowered and proactive management of life, investment in one’s knowledge and skills—is the process by which subjectivity is constructed in the context of the EPP. It is when we consider the other elements aforementioned that hearken to the rationality privileged by neoliberalism, that we come to see that the program is indeed implicated in the construction of a particular kind of participant: one that attests, at least in part, to the manifestation of contemporary public health as a project of neoliberal governmentality.

Conclusion

From this cursory glance at the EPP, it is possible to demonstrate how contemporary public health practices reflect the underlying political rationality of neoliberal government. The very fact that public health manifests itself as an arena of neoliberal governmentality disables a number of scholars and practitioners within that community from exploring how the project of NCD prevention and management—from the construction of risk to treatments and interventions—is a political event.

Skeptics may raise an eyebrow at this assertion, and already the possibilities of doubt appear: “There is nothing political here; disease risk is largely private phenomenon, and to a great extent, an agent chooses to be healthy or no.” There is no doubt that an individual person’s choices and behaviors play an important part in explaining how the onset of NCD; however, to the extent that these decisions and choices have an impact on disease outcomes does not direct our inquiry toward any a priori qualities or faculties of the individual in question. In this regard, from a governmentality perspective on the public health of chronic disease, we are more interested in how particular identities come to be privileged and constructed:

What forms of person, self, and identity are presupposed by different practices of government and what sorts of transformation do they seek? What statuses, capacities, attributes and orientations are assumed of those who exercise authority (from politicians and bureaucrats to professionals and therapists) and those who are to be governed (workers, consumers, pupils and social welfare recipients)? What forms of conduct are expected of them? What duties and rights do they have? . . . How are certain aspects of conduct problematized? How are they then to be reformed? How are certain individuals and populations made to identify with certain groups, to become virtuous and active citizens, and so on? (Dean, 1999, p. 32)

Thus, with the framework employed by this project, we are called to interrogate how particular participant positions and identities are fostered, encouraged, and produced—an interrogation that displays an inherently political character. Although concepts such as “identity” and “agents” are thus under such a rubric decentered, they still constitute an important element in the exploration of public health as a domain of neoliberal government.

At the same time, reflexive consideration of the political character of the EPP, and the larger class of CDSPs that it represents, must bring us back to the US$64,000 question: So what? If the entrepreneurial “can-do!” self is the face of public health governance of NCDs, what are the implications as state and nongovernmental actors attempt to coordinate health governance in the 21st century?

If the British case may serve as an example, the implications seem to suggest the further devolution of public health to local authorities, to the private sector, and to individual bodies. Returning to the 2010 White Paper, the secretary of State for Health asserts that under the new proposed public health reorganization, “Localism will be at the heart of this new system, with devolved responsibilities, freedoms and funding” (Secretary of State for Health, 2010, p. 51). The plan outlines expanded roles for not only local authorities but also charities and volunteer organizations, businesses, and community groups—thus further augmenting the role of the private sector and deepening the ideological ties to neoliberalism (Secretary of State for Health, 2010).

Yet, even as Britain confronts this proposed reorganization of its public health service, we are left to puzzle over the implications of this transition for the governance of public health generally and NCDs specifically. Although framed as reorganization, this trend toward neoliberalism in the NHS is several decades in the making; the spirit of social welfarism that gave rise to the system after World War II has slowly eroded. That cannot be parsed down to simple party politics or transitions of power; indeed, it was under “New Labour” that the hyper-neoliberal EPP was first conceived and deployed. The system also began shifting in the 1990s to use competitive contract bidding, increased public–private partnerships, and other market reforms (Koen, 2000). Yet, if the increasing neoliberalization of British public health has been so effective, why does the secretary of State for Public Health bemoan the fact that...

Britain is now the most obese nation in Europe. We have among the worst rates of sexually transmitted infections [STIs] recorded, a relatively large population of problem drug users and rising levels of harm from alcohol. Smoking alone claims over 80,000 lives every year. Experts estimate that tackling poor mental health could reduce our overall disease burden by nearly a quarter. Health inequalities between rich and poor have been getting progressively worse. We still
live in a country where the wealthy can expect to live longer than the poor.

The dilemma for government is this: it is simply not possible to promote healthier lifestyles through Whitehall diktat and nannying about the way people should live... We need a new approach that empowers individuals to make healthy choices and gives communities the tools to address their own particular needs. (Secretary of State for Health, 2010, p. 2)

To understand then the logic, it is under a more neoliberal approach to public health governance that the current health environment has emerged; it is characterized by a high prevalence of obesity, of tobacco consumption, of sexually transmitted infections (STIs), and of health inequalities. It is precisely those kinds of health outcomes that sparked the White Paper and the proposal for restructuring. Yet, the solution is... more neoliberalism?

Governance, of health or of anything else, is multifaceted. To the case presented here, patients may be experts in their own chronic condition, and they have a role to play in saving themselves. But as we confront the challenges posed to global health governance and consider the accelerating problems of chronic illness, it remains to be seen who will save them from the myopia of a public health system whose claim to being public grows increasingly tenuous.

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Notes

1. Although this characterization of epidemiological and public health work is not universally held, it has been articulated by a number of practitioners as an aim or ideal to work toward. See, for example, Public Health Leadership Society (2002); Rothman and Poole (1985); Rothman, Adami, and Trichopoulous (1998); and Thompson (2001).

2. The inherently neoliberal character of the Expert Patients Programme (EPP) will be more thoroughly detailed in subsequent sections, but these features of the EPP Community Interest Company (CIC) are worth briefly noting to set the stage for that analysis to follow.

3. The report does not provide a specific figure regarding the percentage of primary care trusts (PCTs) that employed this technique. However, the second most widely used practice was media advertising, with 78% of PCTs using this strategy. Thus, we can surmise that the proportion of PCTs using leaflet advertising was quite high.

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Bio

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