

Healthcare in a land called PeoplePower: nothing about me without me

Tom Delbanco MD¹, Donald M. Berwick MD², Jo Ivey Boufford MD³,
S. Edgman-Levitan PA⁴, Günter Ollenschläger MD⁵, Diane Plamping PhD⁶
and Richard G. Rockefeller MD⁷

¹Harvard Medical School, Beth Israel Deaconess Medical Center, Boston, USA, ²Institute for Healthcare Improvement, Boston, USA, ³Robert F. Wagner School of Public Service, New York University, New York, USA, ⁴The Picker Institute, Boston, USA, ⁵Agency for Quality in Medicine, Cologne, Germany, ⁶Tower Hamlets Community Healthcare NHS Trust, Mile End Hospital, London, UK, ⁷Health Commons Institute, Falmouth, ME, US

Abstract

Correspondence

Tom Delbanco
Harvard Medical School
Beth Israel Deaconess Medical Center
330 Brookline Avenue, LY 310
Boston
MA 02215
USA
E-mail: tdelbanc@caregroup.
harvard.edu

Accepted for publication

29 September 2000

Keywords: electronic medical records, employee satisfaction, patient satisfaction, shared decision-making, volunteerism

In a 5-day retreat at a Salzburg Seminar attended by 64 individuals from 29 countries, teams of health professionals, patient advocates, artists, reporters and social scientists adopted the guiding principle of ‘nothing about me without me’ and created the country of PeoplePower. Designed to shift health care from ‘biomedicine’ to ‘infomedicine’, patients and health workers throughout PeoplePower join in informed, shared decision-making and governance. Drawing, where possible, on computer-based guidance and communication technologies, patients and clinicians contribute actively to the patient record, transcripts of clinical encounters are shared, and patient education occurs primarily in the home, school and community-based organizations. Patients and clinicians jointly develop individual ‘quality contracts’, serving as building blocks for quality measurement and improvement systems that aggregate data, while reflecting unique attributes of individual patients and clinicians. Patients donate process and outcome data to national data banks that fuel epidemiological research and evidence-based improvement systems. In PeoplePower hospitals, constant patient and employee feedback informs quality improvement work teams of patients and health professionals. Volunteers work actively in all units, patient rooms are information centres that transform their shape and decor as needs and individual preferences dictate, and arts and humanities programmes nourish the spirit. In the community, from the earliest school days the citizenry works with health professionals to adopt responsible health behaviours. Communities join in selecting and educating health professionals and barter systems improve access to care. Finally, lay individuals partner with professionals on all local, regional and national governmental and private health agencies.

Introduction

World-wide, health professionals scramble to improve the quality of health care, focusing on everything from changing roles for a wide range of health workers, to new technologies, physical plants, education for patients and professionals, and the allocation of resources. These days, virtually every health organization is knee-deep in 'redesign'. Few, however, invite patients to join in such efforts. Consensus reached at a 1998 Salzburg Seminar entitled 'Through the Patient's Eyes', suggests that efforts to improve care might take strikingly different shape if patients worked as full partners with health professionals to design and implement change. To illustrate this point, we summarize recommendations that emerged from intense debate and discussion among 64 individuals from 29 countries over the course of 5 days.

Founded in 1947 in the spirit of post-war reconciliation, the Salzburg Seminar offers a neutral forum in Salzburg, Austria, where individuals from around the world express, challenge and examine their beliefs and those of others on a wide range of topics.¹ The seven faculty for our Seminar, active in clinical care, medical education, health policy, community development, quality improvement, consumer advocacy and shared decision-making, facilitated the work of 57 Fellows nominated and sponsored by national and local agencies, practices or communities. The faculty and Fellows (whose median age was 40) represented nations as diverse as Australia, Argentina, China, Romania, Russia, Sweden, South Africa, Malta, Israel, the United States and the United Kingdom. They included physician assistants, practitioners of alternative medicine, patient advocates, health educators, doctors, healthcare administrators, social scientists, nurses, philanthropists, medical reporters, a storyteller and a theatre artist.

In the introductory group meeting the Fellows developed a guiding principle for patient/citizen involvement: 'Nothing about me without me', an emphatic statement that posed difficult challenges for the week's work. To foster imagination

and creativity, the faculty charged the Fellows with incorporating this principle into a new health care system for a mythical republic called PeoplePower. There, the new prime minister swept into office promising to design an entirely new health system through a joint effort by her lay and professional citizenry. She commissioned the Seminar participants to develop a 'personal health care system for PeoplePower' and, in order to stimulate creativity, she announced that any discussion of 'feasibility' would be left for another occasion.

Working in small teams late into the night, the Fellows elaborated initiatives involving individual patients and clinicians, hospitals, communities and the government, both federal and local. For each initiative, we describe the principal recommendations that won consensus for the foundation of the new system. Reflecting our shared aspirations, we describe PeoplePower as if it exists. Indeed, what follows is consciously 'Utopian', reflecting hopes and aspirations unleavened by the multitude of conflicts and pressures that competitive, materialistic societies engender.

The clinician-patient relationship

Where technologically and financially feasible within the widely varying regions of PeoplePower, computer-based guidance and communication systems are central to the new health care system. They serve not as a replacement for the clinician-patient relationship, but to enhance it at every turn, while dramatically reducing human error. Electronic patient records provide the backbone for decision support systems, as well as a focal point for the clinician-patient interaction. Patients and clinicians depend heavily on secure electronic mail for communication² and a growing number of technologies help patients monitor symptoms and signs in the home. Patients and their families use these technologies also to monitor adherence to medical regimens,³ profiting from reminders such as electronic alerts and diaries.⁴ Higher level guidance, including patient-specific disease management, preliminary diagnosis and triage for

patients at home, and even higher-level diagnostic assistance for patients and doctors together, are increasingly employed and continuously improved.

Medical records and patient education

In PeoplePower, the Internet-based patient record exists as a single version that resides nowhere but is available everywhere. Oversight by many users has greatly improved its reliability. Not only do patients have nearly complete access to their medical record (although they don't have to review their record if they don't want to), but they also write in it – elaborating, tracking and explicating problems, correcting mistakes, prioritizing needs, and at times suggesting both diagnoses and treatment plans. Controlled layering of access provides far greater confidentiality than was previously possible. Some parts of the record are for patients' eyes only. Others, such as clinicians' reminders to themselves, are off limits to anyone else, while employers, payers, etc., are privy only to information authorized for their specific purposes.

In clinicians' offices throughout PeoplePower, computerized voice recognition systems record encounters in real time, allowing patients to go home with a hard copy of the visit to review at leisure thereafter. Others leave the clinician's office with a transcript recorded on a 'smart card', a machine-readable computerized storage system that holds also their medical histories, prior visit transcripts, medication lists and results of health maintenance and diagnostic testing.⁵ Benefiting from PeoplePower's national obsession with secure and private communication lines⁶ still other patients access and shape their medical records via the World Wide Web, offering their clinicians access to information that the patients, and sometimes their families, elaborate and update regularly.

In PeoplePower, most patient education does not take place during the actual patient-clinician encounter. Rather, much occurs before and after visits to clinicians, with patient-specific materials flowing by e-mail from the clinician to patient.

Community-based teams of lay persons and health professionals monitor and recommend interactive material from selected Internet sites, which complements and amplifies the clinical issue at hand.

Citizens from areas in PeoplePower lacking resources for such technologies subscribe enthusiastically to the same underlying principles⁷ but rely on paper and pencil and, when possible, the telephone to communicate. In these parts of the nation, family members, volunteers or small audio or video recorders document interactions in the clinician's office. For educational material, patients and clinicians draw regularly on libraries of books, articles and tapes focused on health promotion and the management of illness.⁸ Peer counselling for those who are not literate plays an important role in elaborating informed, shared decision-making, which represents PeoplePower's national standard for clinical interaction.⁹

Clinicians and patients measuring and improving quality

Whichever technology they use, after patients and their families reflect on and, when possible, review transcripts of the visit, health providers expect to receive anecdotal feedback, sent through secure e-mail systems when feasible. In addition, whether through face-to-face interview, paper and pencil, telephone, or with computer-assisted technologies, virtually all patients complete structured surveys that assess quality 'through the patient's eyes', providing data that guide clinicians in 'real time' towards improved care.^{10,11}

In PeoplePower, each citizen also owns an individual 'quality contract', agreed to and monitored by both the patient and clinician. As an example, consider a middle-aged obese, hypertensive and diabetic man. He and his doctor jointly design a programme to manage his care and together establish explicit, measurable goals for the year. The patient decides to lose 10 kg of weight, decrease his elevated glycosylated haemoglobin level by 2%, and bring down his mean diastolic pressure by 15 mm. To do this

he works to change his eating habits, increase his exercise, and adjust and adhere to his medical regimen. For her part, his doctor agrees to choose and send the patient relevant teaching materials available on the Internet, to review and respond at least quarterly to the patient's electronic diary, and to meet with him three times annually to monitor progress and address new issues.

Both the patient and clinician measure and score performance and outcome, with the relative value of their specific goals enumerated in advance. Incomplete achievements – only 2 kg of weight loss, or tardy responses by the clinician to a patient's e-mail and telephone queries – yield lower scores. The goals the patient and clinician establish include quantifiable measures that document change in functional status and quality of life. In addition, errors and potentially preventable adverse outcomes affect the scores, as does the patient's evaluation of specific elements of the clinician's behaviour, with particular emphasis on the recognition of individual dignity, preferences and needs. If all goes perfectly during the year, the patient and clinician each earn 100 points.

When viewed in the aggregate, the PeoplePower Quality Measurement and Improvement System addresses both the process and outcome of care and reflects both patients' and clinicians' performance. For example, in one 10 000-patient practice in PeoplePower, patients achieved last year a mean Patient Quality Score of 63 out of a 'perfect' 100. The practice and its patients have jointly established a target score of 70 for the current year and together are elaborating strategies to achieve their goal. Similarly, for the 15 clinicians in the practice, last year's mean Clinician Quality Score was 68. This year, helped by a team of patients, the clinicians are working hard to improve care and have targeted a score of 80 as their collective goal.

Research, data management, and confidentiality

Placing the medical record front and centre and developing metrics to judge quality that are

unique to each individual's personal circumstance forces PeoplePower to consider actively the issues of privacy, confidentiality and consent for clinical research. PeoplePower is urging its citizens to 'donate' their own Individual Health Data Account voluntarily and anonymously to the PeoplePower Data Banks. The Data Banks store data that generate and track the various scores outlined above. They also afford the country unique opportunities to aggregate data, establishing a 'virtual' national laboratory that houses standardized, core measures of the processes and outcomes of care. Investigators draw on this invaluable source of data to conduct evidence-based, epidemiological research that informs and improves care throughout the nation and beyond.

Patients in PeoplePower may choose clinicians well-matched to their individual preferences by reviewing taped statements offered by individual clinicians and some of their patients. The videos describe attributes such as the clinician's background, training, experience, practice style and personal preferences. For each clinician, the videos also display anecdotal and aggregate feedback from patients, along with scores outlining and analysing clinical performance.

Finally, PeoplePower rewards all citizens for their contributions to the public's health by providing rapid access not only to their medical records, but also to summaries of their data accounts, presented in ways that consider an individual's literacy, education and cultural needs.

Hospitals in PeoplePower

PeoplePower is experimenting with a system of accountability for patient advocates that mirrors one in place in several newspapers in the United States. As an example, the *Boston Globe* ombudsman who critiques articles appearing in that newspaper reports to the owner, not the editor. Similarly, ombudspeople in PeoplePower report to the ultimate hospital authority, beyond the chief executive or his or her delegates. From that prominent and protected vantage point, the ombudspeople spearhead efforts to improve care

by scrutinizing untoward patient experiences and advocating timely remedies.

Collaborating with social scientists, the ombudspople also join teams of hospital workers who generate from patients and their families a constant stream of feedback, both through surveys designed to provide aggregate data and by inviting individual anecdotes. Guided by the principle that an efficient, energized and satisfied workforce provides the best care, the ombudspople and social scientists gather similar information from the hospital workforce, including professionals and those in supporting roles, using surveys that measure workers' experiences in carrying out their responsibilities and also evaluate job satisfaction.

On PeoplePower hospital floors, families help not only their loved ones, but also volunteer to aid many patients in the hospital. Similarly, patients join in a wide variety of hospital efforts, ranging from *ad hoc* work teams developing new initiatives, to the array of committees overseeing different hospital functions. Such patient participation provides further substance to PeoplePower's 'nothing about me without me' guiding principle.

With respect to hospitals and their physical design, PeoplePower recognizes that individual preferences concerning privacy vs. group living vary widely. Much like the stage in a theatre, the nation is building hospitals that house rooms of changeable shapes and sizes, thereby helping staff and patients adapt to shifting usage and preferences. Where resources permit, each room holds an information centre, including the patient's electronic medical record, a computer providing Internet access, CD ROMs offering education about disease and the processes of care, and recording and playback devices that allow patients and families to review important discussions with caregivers. Volunteers help 'low tech' patients work with these technologies.

Wherever feasible, hospitals in PeoplePower bring natural light to the patients and workforce, gardens are abundant, pet animals are welcomed, and there is a sense of campus, rather than prison. Hospitals support patients further by allocating space to non-governmental organizations

(NGOs) representing the categorical interests of both healthy and ill individuals. Further promoting a mix of professional and lay skills, the hospitals house associations focusing on diabetes, cancer, care at the end of life, parent counselling or addiction. Hospital-based learning centres and libraries, similar to those pioneered by Planetree in the United States,¹² take a central role in convening and networking patients and their families and friends. The centres work closely with storytellers who both perform for patients and elicit patients' stories, artists and performers from a wide range of disciplines, spiritual leaders from the community, and healers from a broad spectrum of disciplines that complement allopathic medicine.

Community-based initiatives

In communities throughout PeoplePower, primary care clinicians serve as 'gateopeners', in striking contrast to their former role as 'gatekeepers'. Community leaders work closely with health professionals and their students to encourage 'community-oriented primary care'¹³ that actively engages primary and secondary schools, religious institutions, local businesses, the police force and prisons. In the elementary schools in PeoplePower, health professionals join teachers in preparing students from their very first days to take steps to maximize their own health and to learn to deal with illness in a way that promotes informed, shared decisions between themselves and those who care for them.

Lay citizens and clinicians join in educational initiatives designed to improve clinical, spiritual and managerial skills among health professionals and lay individuals involved in health care. Acknowledging PeoplePower's national interest in developing health professionals with cultural and ethnic backgrounds similar to those they will serve, community representatives help identify candidates suitable for careers in health care and join in the selection process for new health professionals. Holding formal teaching appointments in health profession schools, both healthy and ill lay persons teach young health

professionals how to understand and draw upon the patient's perspective.¹⁴ Apprenticeship programmes deploy healthcare leaders as mentors to those demonstrating particular promise as future leaders.

Peer counsellor programmes match patients in need with individuals with similar clinical conditions and health needs. Individuals in local healthcare volunteer corps serve as 'navigators', assisting patients with the services of NGOs, hospitals and practices providing ambulatory care. Those helped by such efforts are expected, when possible, to reciprocate by volunteering their services for other community needs. Thus, for those capable of participating, a service credit 'barter system', similar to the 'time-dollar' initiatives emerging in some communities in the United States, encourages people from all walks of life to contribute to the PeoplePower health system.¹⁵

While much of the foregoing draws on voluntarism and reciprocity, such a system requires a robust infrastructure. Helped by the federal government and private philanthropies, communities throughout PeoplePower take the lead in providing financial support that builds voluntary efforts into the fabric of the nation.

National and local governmental agencies

In PeoplePower, those who legislate, regulate and pay for health care work closely with patient advocacy councils and include lay representatives on their principal committees, working groups, review boards and consensus panels. Similarly, the ministries of health and corresponding local agencies have established high level positions for individuals charged with articulating and monitoring the patient's perspective.

National and local quality task forces contain a mix of health professionals and lay individuals. They establish and monitor quality standards that amplify and aggregate the individual quality contracts and improvement initiatives outlined above. They work aggressively to identify 'benchmarks' and 'best practices' that stimulate efforts to improve care. The goal is a level of

service that delights and surprises both the 'caregiver' and 'caregetter' with unanticipated levels of excellence.¹⁶

Led by the national government, PeoplePower is establishing a 'patient bill of rights', developed collaboratively by professionals and patients. It moves beyond current efforts, as the nation works to build consensus on complex issues such as priorities for organ transplantation, mental health care, entitlements for the poor, genetic engineering and therapies, and care at the beginning and end of life.

In an effort to hold the media accountable, a national programme to inform and educate the media has established guidelines for fairness and accuracy. National and local agencies assist and support the media in recruiting and retaining experts skilled in interpreting research studies who teach reporters to evaluate new findings critically. PeoplePower has also established incentives, including national and local 'health-care media award programmes', that encourage the media to join in efforts to improve the health of the nation.

Finally, accountability for health and illness in the nation sits at multiple levels, such that every citizen is growing confident that 'nothing about me without me' is embedded in all levels of the delivery system. Accountability is becoming transparent, functioning upward, downward and horizontally, with quality measured at every juncture. Indeed, as 'infomedicine' becomes an equal partner with 'biomedicine', all citizens of PeoplePower share accountability for the quality of the new health system.

Summary

We paint the components of PeoplePower's mythical health system with a broad, utopian brush, and the landscape that emerges differs strikingly from the strategies, shape and philosophy of care deployed today in health systems around the world. It is a scenario divorced entirely from financial, human, societal and historical constraints, and as such is suspect, can never be realized in its entirety, and indeed runs the risk of appearing cloying, simplistic and

beyond any possibility of approaching realization. Yet, examples of many of the components the Seminar envisioned exist, or are being developed somewhere today. The underlying principles – that of production, governance and accountability shared and created by patients working closely with health professionals – engendered visions among the faculty and fellows that provoked animated debate well into the night. At a time of frightening instability and change in health systems world-wide, our hope is that the readers of *Health Expectations* will be similarly stimulated to work towards health programmes that draw closer together patients and those who care for them.

Acknowledgements

The authors thank the session Fellows and observers for the insights and creativity that engendered the body of this paper. Thanks also to Patty Russell BA for her assistance throughout the Seminar and thereafter in the preparation of this manuscript, and to Erin Hartman MS for editorial assistance.

The Seminar was supported by contributions from the Robert Bosch Stiftung GmbH, the Branta Foundation, Bure Health Care, The Commonwealth Fund, Fairview Medical and the Fetzer Institute.

References

- 1 Ryback TW, Fox S, Ryback ML. *The Salzburg Seminar: the First Fifty Years*, 1st edn. Salzburg, Austria: The Salzburg Seminar in American Studies, 1997.
- 2 Kane B, Sands DZ. Guidelines for the clinical use of electronic mail with patients. The AMIA Internet Working Group, Task Force on Guidelines for the Use of Clinic-Patient Electronic Mail. *Journal of the American Medical Information Association*, 1998; **5**: 104–111.
- 3 Slack WV. *Cybermedicine. How Computing Empowers Doctors and Patients for Better Health Care*, 1st edn. San Francisco: Jossey-Bass, 1997.
- 4 Rind DM, Davis R, Safran C. Designing studies of computer-based alerts and reminders. *MD Computing*, 1995; **12**: 122–126.
- 5 Neame R. Smart cards – the key to trustworthy health information systems. *British Medical Journal*, 1997; **314**: 573.
- 6 Rind DM, Kohane IS, Szolovits P *et al.* Maintaining the confidentiality of medical records shared over the Internet and the World Wide Web. *Annals of Internal Medicine*, 1997; **127**: 138–141.
- 7 Mandl KD, Katz SB, Kohane IS. Social equity and access to the World Wide Web and e-mail: implications for design and implementation of medical applications. *Proceedings of the AMIA Annual Fall Symposium*, 1998: 215–219.
- 8 Barzda L. A voluminous library for what ails you. *New York Times*, Connecticut Section, 1999; 4 July.
- 9 Rockefeller R. Informed shared decision-making: is this the future of health care? *Healthcare Forum Journal*, 1999; **42**: 54–56.
- 10 Cleary PD, Edgman-Levitan S. Health care quality. Incorporating consumer perspectives. *Journal of the American Medical Association*, 1997; **278**: 1608–1612.
- 11 Gerteis M, Edgman-Levitan E, Daley J, Delbanco TL. *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*, 1st edn. San Francisco: Jossey-Bass, 1993.
- 12 Werdal L. Through the patient's eyes. The Planetree experience at Griffin Hospital. *Healthcare Forum Journal*, 1995; **38**: 35–38.
- 13 Mullan F. Sounding board. Community-oriented primary care: an agenda for the '80s. *New England Journal of Medicine*, 1982; **307**: 1076–1078.
- 14 Delbanco TL. Enriching the doctor–patient relationship by inviting the patient's perspective. *Annals of Internal Medicine*, 1992; **116**: 414–418.
- 15 Cahn E, Rowe J. *Time Dollars: The New Currency That Enables Americans to Turn Their Hidden Resource – Time – Into Personal Security and Community Renewal*, 1st edn. Emmaus, Pennsylvania: Rodale Press, 1992.
- 16 Berwick DM. The total customer relationship in health care: broadening the bandwidth. *Jt Comm Journal of Quality Improvement*, 1997; **23**: 245–250.