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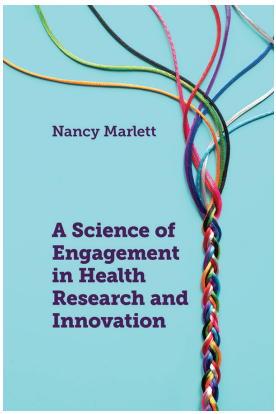

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

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9

Patient Perspectives of Health Systems

> *You cannot understand a system until you try to change it.*
> (Lewin, 1951)

Highlights

- Evolution of health systems in Canada
- Discovering ways to depict health systems from patient perspectives
- Using a patient perspective of health systems to explore patient roles and opportunities for change
- Analyzing systems using crowdsourcing, narrative, and discourse analysis
- Examples of emancipatory systems from seniors, social enterprise, etc.

I have always been intrigued by the influence systems have in our daily lives. This interest began in the 1960s, first on a closed ward for women with complex behaviours, and then as the director of a psychiatric vocational training program for patients hoping to find employment. The power of changing routines that impact the nature of experience couldn't be denied as women behaved as expected to gain access to their meals and treats. I moved to Alberta and joined a social innovation that trained people with disabilities for employment and worked with community rehabilitation programs across ages and conditions.

When I was hired to develop the community rehabilitation and disability program of studies at the University of Calgary and later hired as a faculty member, I turned to social construction to study and influence the power of systems on individuals, emerging community programs, and access to health, social care, and employment (Marlett, 2021; also reproduced in the Resources section of this chapter). My intrigue with systems motivated my research in education, healthcare, long-term care, welfare, guardianship, and social service

systems. All shared hierarchical structures of staffing and decision-making, professionalization, low-paid frontline staff, and rigid criteria related to client expectations and access to resources. Access to care depended upon adherence to expectations.

This chapter proposes a different look at systems from a client/patient perspective. It combines subsystems and includes systems that exist outside of the formal health systems. The goal is to provide a template that can be used by patients and shared with service providers and researchers to understand systems as constellations of services and supports from a patient perspective. This theory enables individuals and groups to use information about health systems to guide the specific systems they use, both inside formal systems and within community options.

Evolution of Healthcare Systems

In order to understand current healthcare and the potential futures of health systems, let's look at how health systems became so large and entrenched supported by health research. After the Second World War, societies around the world struggled to reestablish social order and looked to the dominant industrial and military systems as models. Healthcare grew through industrial models, adopting reliance on evidence, influenced by Japan's industrial model that was based on extreme evidence-based statistics. This evidence foundation became known as continuous quality improvement (CQI) or total quality management (TQM). These provided the scientific, statistical foundations, clear authority hierarchies, and evidence-based decisions that supported standardized care protocols.

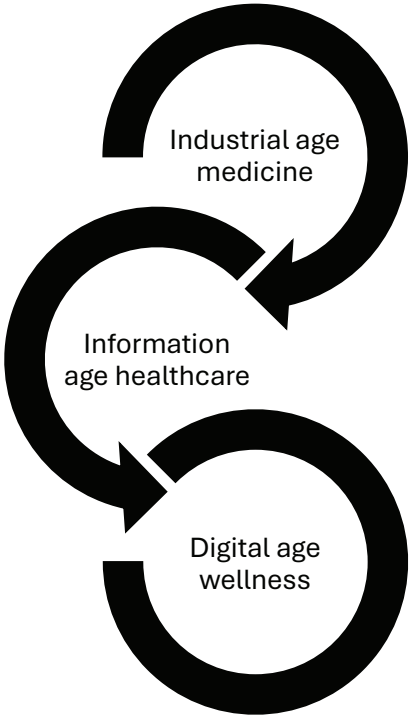
As industrial age medicine and medical science merged to create strong science-based health systems, the resulting model justified government funding and control, along with the development of health professions to maintain the institutional structures. Professions, supported by science and secure funding, produced medical evidence-based definitions of service and standardized interactions between citizens and professionals. In this process, deviance became formalized as a criterion of eligibility, along with 'due process' to control deviance.

By the second half of the century, citizens and new social movements reacted against the impact of large, standardized health systems as they experienced increasingly restrictive systems and lost identity, control, and independence. Professionals experienced a loss of autonomy in their practice, depersonalization, and loss of effectiveness as protocols were adapted to be done by less expensive and less qualified staff. Governments, who saw costs and expectations rise, then sought to reduce costs by privatization, downloading care to families and less expensive care providers, while tightening eligibility criteria.

During this time design thinking, social enterprise and innovation, and citizen science responded to advances in information technology and computing. Artificial intelligence and machine learning began addressing issues that had normally been part of health systems. In particular, health technologies were being designed outside of health systems to respond to profound societal changes within our entrenched health systems. If we are to make a difference to existing healthcare and research systems, we need to look outside of health systems to patients and communities, new action research models, and flexible and nimble change strategies. Regardless, the future seems poised to become more democratized with complementary, traditional, and community-based health. Health systems from a patient perspective include services both within and outside of the existing healthcare systems.

Figure 9.1 attempts to depict the nature of the healthcare system transformation.

Figure 9.1 *Anticipated Change from Industrial to Information to Digital Medicine*



Information age or digital healthcare provided the impetus for the beginning of the PaCER program. Patients who responded to our recruitment were eager to use their newfound online information to improve their health and the healthcare system. They were early adopters of digital wellness that includes our ability to prevent or lessen the burden of many chronic and stress-related conditions.

We also need to address the growing wicked problems in healthcare and research, which includes natural aging of systems and healthcare and stakeholders that reify complexity, competition, and bureaucratic barriers. Wicked solutions, on the other hand, are more likely to be found in localized initiatives that focus on specific concerns that reduce complexity, and peer research is a natural example of a local or self-contained research model. Luckily, health research already operates at the level of localized health conditions and services based on age, pathways, and types of service communities that come together with shared experience and knowledge. At this level it's possible to use JEDI principles to categorize systemic obstacles in research. Increasingly, research grants include more support for diversity and inclusion to support goals of open innovation in science (OIS), responsible research and innovation (RRI) that promote research that is democratic, creative, and nimble.

PaCER training has the advantage of working with diverse, local, and targeted health research grants, sponsored by research teams interested in patient perspectives on clearly defined, local concerns. For example, one PaCER class included families with experience with intensive care, another with recent immigrant women with early-stage cancer, and another with patients with chronic kidney disease. In this environment PaCER students conduct patient experience research related to the topic of their research learning about equity, diversity, and inclusion and common challenges in access to healthcare. Democratizing research is best done by including communities, patients, and citizens as partners from co-design to healthcare implementation.

Health-related citizen groups, such as Imagine Citizens (https://imaginecitizens.ca/), are involved in collective citizen research. The largest collective patient voice is the International Alliance of National Patient Involvement in Research, which includes partners such as INVOLVE UK (https://www.nihr.ac.uk/health-and-care-professionals/engagement-and-participation-in-research/involve-patients.htm), PCORI USA (https://www.pcori.org), SPOR Canada (https://cihr-irsc.gc.ca/e/41204.html) and Consumers Health Forum Australia (https://chf.org.au), that support recruitment into research studies and increasingly support patient, clinician, and patient researcher collaborations. Independent peer-led research is gaining a foothold in establishing a patient research voice outside of traditional health research grants.

Other key actors in gender, race, culture, and age-based movements rely on shared wisdom and collective action to challenge systemic discrimination in health practice and policy. Women's, Indigenous, disability, race, and aging studies academic programs have been able to create emancipatory research voices based in critical theory foundations that support the need for change and support localized research. Ashoka changemaking social enterprise (https://www.ashoka.org/en-ca) provides a different perspective, in that the engagement for change begins when citizens come together with innovators to share experience, ideas, and potential for change.

Perhaps the most significant force for systemic change in health research is emerging with a dramatic challenge to the way research is funded and conducted. Luna is an American data-sharing platform for rare conditions and diseases founded by families frustrated by the lack of research or treatments, which has become a public benefit corporation (National Academy of Medicine, 2022, https://doi.org/10.17226/27107). The corporation has changed the roles of patients and families from anonymous research subjects to partners of discovery. The corporation is funded by biotechnology companies and venture capital organizations to provide better ongoing connections between research participants and researchers and give participants direct control over how their data are used. This includes ownership shares with cash dividends.

A Canadian social enterprise started from the urgent need to locate cancer research opportunities to extend the life of a cancer patient, Zamplo, with Alberta Cancer Foundation support, empowers individuals with the knowledge and tools to curating their real-world data (Zamplo, n.d., https://www.zamplo.org/). Zamplo Research connects researchers to patients and caregivers and supports online research opportunities.

The options for new patient-centred research partnerships are growing rapidly. Many patients have found ways to become agents in detection, decision-making, treatment, and ongoing monitoring both inside health systems and as part of the large network of complementary health providers. These patients could easily transform into citizen scientists, from early detection to technology driven treatments. This may seem like a brave new world scenario, but monitoring and treatment implants are already in early stages with non-communicable diseases and stress-related health problems that should include patients as part of innovation teams. Patients in Alberta already have access to digital health records and reports. Every day new technologies to monitor symptoms, diet, and exercise come on the open market. They use their access to internet health information to learn about medical conditions online and connect with the networks of other patients with similar issues.

In this chapter, we propose that health systems benefit from investing in building capacity for peer research that informs research on existing practice and innovation. Patients can be engaged through chronic care hubs that are becoming dynamic, engaged platforms that encourage patient sharing and patient control of monitored and patient-provided data. This combines the formal evidence-based goals of health and emancipation of patients who could use the science of engagement to become peer research–informed chronic care supporters for in-home care. Unlike academic research, the focus of new models uses innovation research models that are nimble and able to change as needs and technology change. Most of these initiatives begin with the expectation that new options will include community and patient participants.

The following section introduces alternative views of health systems that were used to design a theoretical model for the last section, which describes health systems from four perspectives.

Alternate Views of Health Systems

The concept of healthcare based on real-life experience can help patients, communities, and health professionals create new views of a health system. This is already happening online, with organizations such as Maple (https://www.getmaple.ca/) and chronic care online health hubs. Maple has evolved into a health system to provide acute, chronic, and specialist care support to remote and marginalized populations and fill the gaps in our provincial health systems. They may include existing professionals and new options such as nurse practitioners, paramedics, and health technology assistants along with peer health navigators and peer support. The online health networks and condition-specific care hubs provide alternatives to more formal systems. This is where the potential of information and digital age medicine currently resides. These new paradigms encourage us to move beyond industrial age medicine, where the system provides for the health of patients, and information age medicine where access to information is open to patients, to digital health, and to new forms of health systems that include community options.

We now look at social-ecological system frameworks that have informed the study of how systems impact seniors or PWLE living with conditions such as mental health, disability, and a range of acute and chronic health conditions. My first exposure to social ecologies emerged while working in Russia and Japan, where I was part of developing community options to extend existing health systems. Most recently, social ecologies of health systems have been used as part of a consultation to identify how patients see their primary care health systems done with the Health Quality Council of Alberta (HQCA) and a design thinking course for senior undergraduates and graduates as part of disability

studies. The final model presented a template to identify systems patients use, or could use, to deal with their health concerns as part of peer research.

This chapter now moves to the social ecology of healthcare and research systems that patients and their families rely on in the attempt to explore how emancipatory science and the unique contextual factors patients encounter in their use of health systems add to the science of engagement. In this, patient health is not quantified or permanent but includes how to extend patient expertise and the capacity of patients and communities to be part of healthcare transformation. The SMART framework in Saskatchewan is a courageous combination of citizen science and participatory research that reflects the direction of the emancipatory science of engagement in health research and innovation (Katapally, 2019, https://doi.org/10.2196/14056).

The forerunners of all emancipatory movements in health are the disciplines and advocacy-based professions that began with women's studies, race studies, Indigenous studies, and disability, aging, and mad studies. These new disciplines are defined by critical theory and focus on changing policy and programs to foster role equity through challenging systemic discrimination and labels. These new programs and services shift from remediating deficits to fostering capacity and rights of patients as stakeholders. These pioneers are fundamentally challenging historical and economic power imbalances in healthcare to lessen systemic discrimination as part of existing health systems.

Increasingly, health and rehabilitation professionals begin their journey as undergraduates in cultural studies programs, learning the foundations of critical thinking. They become more comfortable working in contested spaces, with the ability to create synthesis from multiple standpoints. They are creating innovative communities with peer-based and consumer-driven options within health. Existing rehabilitation professionals are also migrating into community-based wellness and rehabilitation services.

A Peer-Led Investigation of Primary Care Systems from a Patient Perspective

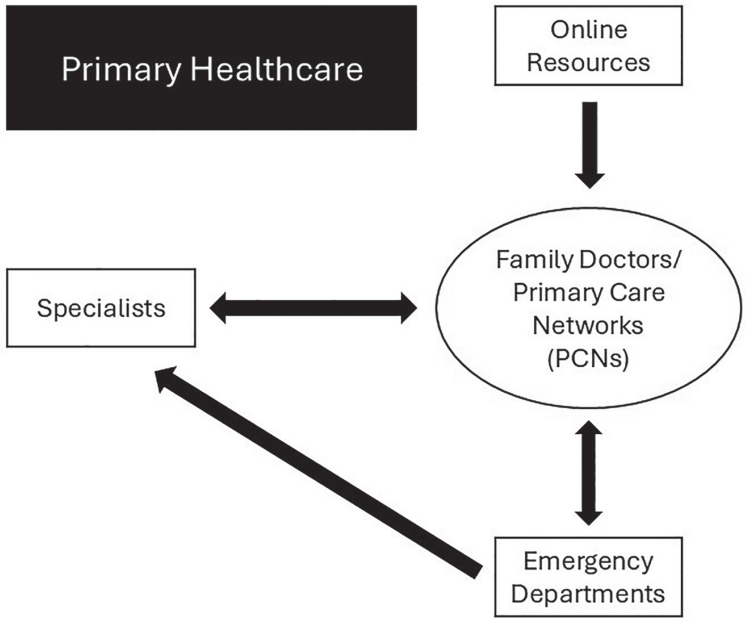
This consultation was carried out by the PaCER program at the University of Calgary for the Health Quality Council of Alberta (https://hqca.ca). The goal was to provide an independent snapshot (map) of the primary care network (PCN) systems from a patient perspective. Patients were recruited from three key groups within primary care—seniors, occasional users, and patients living with chronic and complex conditions. These representatives were recruited from five provincial patient organizations and included urban, small-town, and rural Albertans, a balance of age and gender, with diversity in cultural backgrounds. Patients, PaCER peer facilitators and recorders, HQCA staff, and a

film crew were involved. The film and the information gathered and analyzed were prepared as the introduction to a provincial primary care consultation that would consider future directions from a patient perspective.

Each participant was asked to contribute up to five recent health incidents that required attention, along with the options they considered to address them. Over 240 incidents were identified, and a surprisingly clear picture emerged about their use of health systems at the primary care level. The resources were compiled and categorized as system maps from a patient perspective that identified how patients saw the systems they considered part of their specific health system.

Figure 9.2 represents primary care from the perspective of occasional users. Their health system aligned with the primary care system. They saw primary care with two main connections: the primary care network and specialists. They also recognized their personal use of online resources and emergency departments. This simplified notion of a primary care system reflects a common understanding of most occasional users.

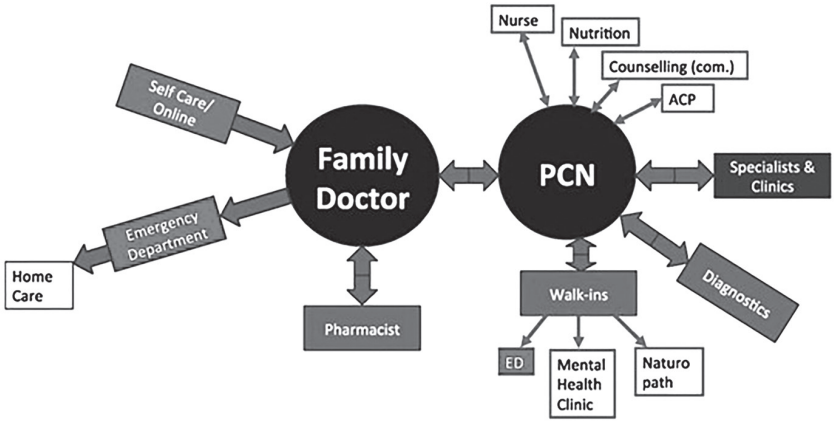
Figure 9.2 *Primary Healthcare from the Perspective of Occasional Users*



Next, in Figure 9.3, we shift to the complexity of the primary healthcare system from a senior's perspective that is grounded by a 'family doctor' as the centre of their health system, along with the doctor's nurse or alternate who provides access to other services. These include ongoing nursing support, nutrition, specialists, diagnostics, and other services. The PCN plays a much smaller role.

The doctor links to the emergency department or hospital for urgent and transitions to services such as home care. There is also an interesting connection between walk-in clinics that suggested links to complementary care and mental health supports.

Figure 9.3 *Primary Care from the Perspective of Seniors*

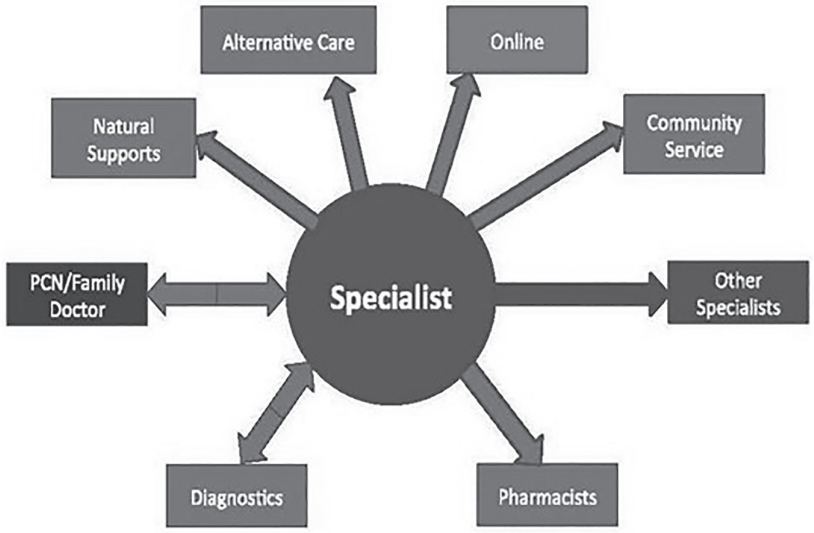


The role of the emergency department was of particular interest as a community resource, especially in rural areas. In addition to handling emergency care and their natural links to hospital services, doctors seem to provide access to specialists, private clinics, and community resources. The link to the emergency department seemed particularly strong, and this mirrored a similar trend in other primary care diagrams as part of this workshop that reflected the after-hours 811 calls.

In Figure 9.4, we see primary care for patients with ongoing chronic and complex healthcare needs. Here, the primary role of the family doctor is replaced by the specialist or specialty clinic. Many of the incident cards spoke of specialist care that was not part of hospital care, but also not part of the PCN. Specialist connections included medical specialists, pharmacists, allied health (private physiotherapy, diagnostics), and complementary health

providers (naturopaths, chiropractors, massage therapy, counsellors, dentists). Natural support included self-help groups such as AA and church programs. Community services included mental health and community rehabilitation agencies for groups such as those with brain injury and strokes, persons with disabilities, and the Alzheimer's Society. This foretells the chronic care hubs that are emerging outside of traditional healthcare.

Figure 9.4 *Perceived Role of Specialists Within Primary Care*



The flow between the PCNs and medical specialties is reciprocal, but participants saw the specialist system as mirroring the role of the doctor. The specialist system is more simplified than other systems and most patients noted that they would prefer that specialists provided more primary care functions rather than going back to their family doctor for referrals.

This report is available in the Resources section of this chapter.

Most of the studies completed with peer research through PaCER are located within existing healthcare systems and some innovative systems designed to overcome systemic barriers. We now pivot to specific examples of how to open the discussion of healthcare systems that have led to significant changes in healthcare delivery. We begin with an early example in Russia that introduced the need for a simple tool to help psychiatrists understand how community mental health might be introduced as part of Russian psychiatric care.

A Community Mental Health System in Russia

I came to understand the power of systems during the collaborative efforts of Community Rehabilitation and Disability Studies (CRDS) at the University of Calgary and the Russian Institute of Psychiatry. The goal of this 10-year collaboration was to expand the Russian mental health system from a reliance on large institutions and to develop community options. This also involved a consumer-led community mental health program called Fountain House (https://www.fountainhouse.org/) that was similar to Clubhouse in Canada (https://clubhousecanada.org/). These three systems: psychiatric institutions, community health professionals and support for Fountain House marked a significant system change for Russian psychiatry (Disability Rehabilitation, n.d., https://www.ijdcr.ca).

In effect, we were introducing social innovation by co-designing a community mental health system. Russian patient members of Fountain House and a family movement were our allies in Russia, and members of our Clubhouse acted as mentors and hosts of the visiting Russian team for each Russia-Canada visit. These patient mentors met the Russian team at the airport, settled them in their accommodations, took them to each session, and acted as their guides and instructors. The Russian team was initially reluctant to be reliant on 'patients,' but soon came to appreciate the capacity of the mentors and the partnerships they formed. It was a powerful tool in readjusting the distinct power differentials that existed in psychiatry in Russia by challenging Russian beliefs about the role of patients as recipients of care for permanent disability.

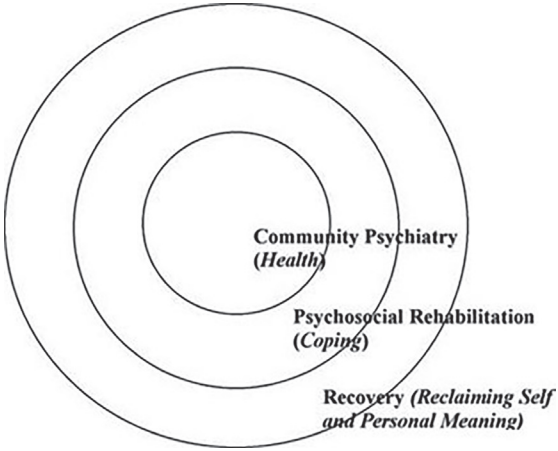
I was responsible for opening a debate about healthcare systems in mental health. We began with our shared focus on science and research. During two weeks of sessions with psychiatrists from across Russia, we discussed common social problems for citizens with mental health concerns—from employment, physical activity, housing, family support, and legal and political issues that were conflated with institutional psychiatry.

During the first few days, all situations produced a common response—refer to the hospital psychiatrist. Carefully, we created hypothetical services and supports that could be created within the community to be offered by other professionals. It was difficult, but as the psychiatrists became involved in a co-design process, they began to see that there could be alternatives to psychiatric hospitals.

The simple tool in Figure 9.5 allowed the participants to experiment with community-based psychosocial subsystems. The outer rim captured the goal of Fountain House, a community mental health recovery system with the goal of reclaiming self and personal meaning as part of an integrated system of peer support. By the end of the sessions, we had created a simple system for

community mental health, consisting of three concentric circles. The article was published in Russian, and the teams met regularly to develop community resources and training programs for psychosocial rehabilitation.

Figure 9.5 *Russian Community Mental Health Template for Creating Community-Based Psychosocial Services*



- The centre combined science and community psychiatry, which was synonymous with all psychiatric support inside and outside of the large institutions (and most often located in the institutions). Psychiatrists were the main professionals, looking after medical interventions, family support, employment, and funding.
- The psychosocial circle represented a separation of medical psychiatry and new professions such as social work and community rehabilitation specialists in work, living, leisure, and physical therapies. This ring was extremely hard to conceptualize because few professional traditions or psychosocial training programs existed apart from psychiatry. This was called a coping circle.
- The outer circle represented recovery, based on the principles of Fountain House about reclaiming useful roles in society and sharing the development of personal meaning through peer support.

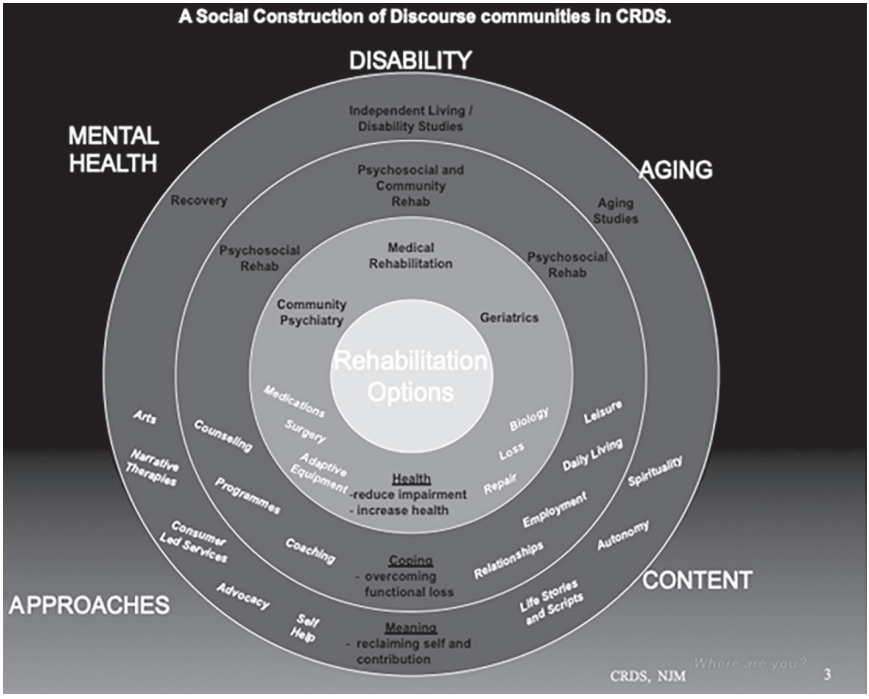
This simple tool was used to develop models for teaching in my home faculty and publications. It has been used with quality improvement, community-based participatory research, peer research, discourse analysis, and program evaluations.

Disability, Aging, and Mental Health Studies

Figure 9.6 is a template of a social ecology of health systems, created as part of the study of health systems related to disability studies programs. The disability section includes:

- Medical rehabilitation that includes diagnosis and treatment, primary care, specialists, and emergency departments in order to reduce impairment and support health of disabled persons, seniors, and those living with mental health challenges.
- Psychosocial and community rehabilitation therapies and clinics, including many complementary options to remediate health-related problems to improve coping skills and the ability to function.
- Independent living and disability/aging and mad studies focus on peer and natural supports and mainstream services, to find meaning and reclaim productive roles that make a difference in their lives.

Figure 9.6 *Health and Healthcare Systems in Disability, Aging, and Mental Health*

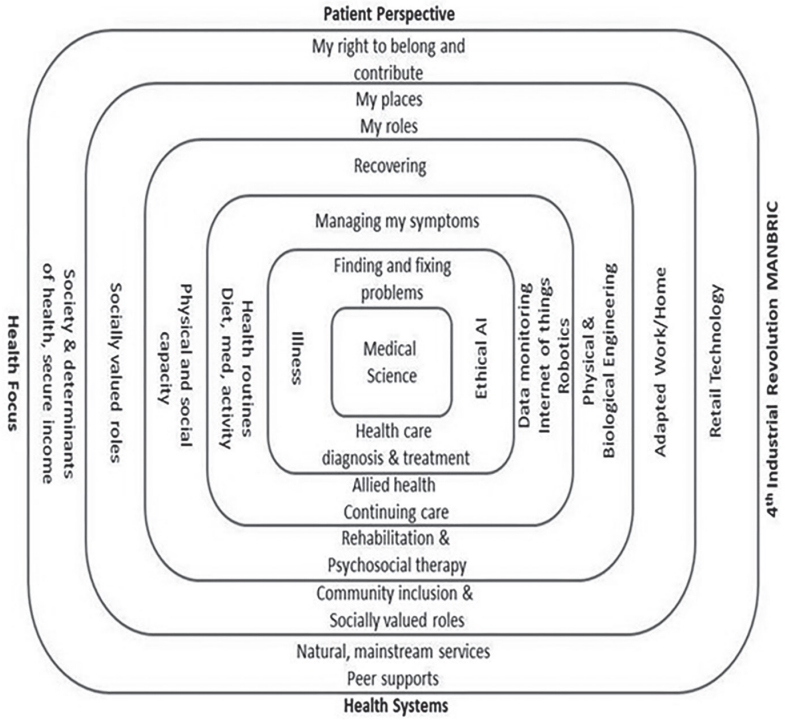


While this was developed specifically for disability, aging, and mental health systems, it can also be applied to systems such as hospitals, acute, long-term, chronic, palliative and primary care. The template can be used to support researchers, both academic and peer researchers, looking to learn about the systems when beginning an action-oriented research project. It can be adapted to identify policies, programs, procedures and relationships for any group or community.

A General Template for Patient Perspectives of Healthcare Systems

The template in Figure 9.7 grew from an attempt to consolidate options identified by students in disability studies, that include medical, nursing, disability studies, and education students. Much of the input came from reviewing Grey Matters and PaCER research projects.

Figure 9.7 *A Patient Perspective of Health Systems*



The Science of Medicine: Biomedical

Science systems have been the driver for health transformation and technology innovations, but new patterns of innovation are also emerging, notably social enterprise initiatives that come from community needs and maker spaces that bring together citizens with diverse talents and interests to create technologies such as 3-D printing to solve pressing problems. This would also include emerging science platforms that include patients and researchers as partners such as PaCER. Science seemed to be a common starting point for all four sides. The following looks at health systems form a patient perspective that draws on the other three sides of the visual theoretical system.

Finding and Fixing Health Problems

Illness focus, healthcare, diagnosis, and treatment using ethical AI technology.

The patient name for this first ring is a practical, almost mechanical view of illness. Healthcare diagnosis and treatment translates science into practice from a health system perspective. In Canada, diagnosis and treatment rests within primary care, with links to specialists and hospitals. It is a pluralistic system of public healthcare delivery, quarterbacked by group physician practices. This operates within the *Canada Health Act* principles with provincial single-payer agreements (Hutchison et al., 2011, https://doi.org/10.1111/j.1468-0009.2011.00628.x). Patients seldom understand the intricacy or politics of federal agreements and provincial healthcare delivery, or how these create obstacles to social change.

Increasingly, when a patient engages with primary care or emergency departments with a 'magic bullet' condition (i.e., an identifiable cause and an approved treatment), the health system can operate with almost big box efficiency. This level of healthcare seems to attract new players because many of the functions of primary care are accessible online. For example, Walmart health clinics provide primary, urgent, senior, behavioural health and dentistry services as an example of a growing global movement to standardize care for routine healthcare needs outside of our current primary care networks. In Canada provincial health plans work with online health providers such as Maple to fill gaps in primary care as an almost automated primary health system for common health issues. These online options could threaten the viability of the 'family doctor,' who is a local ally and advisor throughout life instead of a one-stop shop for existing health problems.

The role of primary care physicians and specialists are changing dramatically with the advent of artificial intelligence and machine learning that enables

collection and analysis of digitized data from a wide array of new sensing and tracking devices, computerized tests, and records. Advanced and personalized algorithms and protocols will become available to patients and a variety of healthcare providers, changing the diagnosis and treatment paradigm currently in place. This suggests that the connection to a primary care practice and staff may be lessened.

Medical professionals are already preparing for these new developments. New information specialists are being prepared to work with patients to help them understand and make decisions based on accessible health data and patient-owned and patient-generated data (Heath, 2022, https://www.techtarget.com/patientengagement/feature/Digital-Health-Literacy-Why-Its-Important-and-How-to-Improve-It). Patients need to prepare to take advantage of these new directions in patient-managed care as healthcare systems transform. Patients can now curate their own health information, share it with treatment options, research opportunities, and connect with others with similar problems to share ideas and combine resources using provincial health platforms and emerging data platforms such as Zamplo. In many ways, new patient-driven ways to use personal data have the markings of incubator spaces that are driven not by systemic problems but opportunities for inclusion in self-care and management. But these new options will only increase the care divide unless using healthcare technology becomes a recognized curriculum in our schools and communities.

Patients are not alone in recognizing the power of deep medicine, private clinics, pharmacies, and new consumer hubs that are using the streamlined diagnostic treatment links to create new options for healthcare of common and chronic health concerns. The issue of ownership of information at this level is hotly contested among health systems, diagnostic systems, patients, governments, pharmacies, and insurance companies, and patients may be included in ownership debates. Whatever the outcome, the increasing patient access and ownership of their personal health data are likely not to be reversed.

In summary, primary care is the first system to be impacted by the fourth industrial revolution and will lead change throughout health systems.

Managing My Symptoms

Allied health continuing care as part of primary care, with a focus on health routines of diet, medication, and activity using data monitoring, the internet of things, and robotics.

Allied health professionals are part of the primary-care health system, especially the support for rural and marginalized groups. These multidisciplinary

teams include health management nurses, clinical pharmacists, mental health professionals, social workers, dieticians, and others as identified by the population being served. These professionals cover a range of healthcare supports under the umbrella of tertiary (symptom management/rehabilitation) prevention (Institute for Work & Health, Toronto, 2015, https://www.iwh.on.ca/what-researchers-mean-by/primary-secondary-and-tertiary-prevention). Patients in these chronic care systems learn to tell new patient stories about themselves. As they are socialized to use new language and routines of clinic protocols, they see themselves defined by their condition and the allied health professionals they rely on. The rising costs associated with chronic care have fast-tracked wearables, implanted sensors, and personalized robots that will alert care providers of concerns as they arise. AI analysis supports online digital interventions that assess and address needs. At this stage, the future of an internet of things (devices) is moving quickly, and the eventual destinations and outcomes are anyone's guess.

As the aging population increases the need for chronic care, it is important to seriously consider what is happening in the United States that is poised to face competition from retail health providers such as Walmart, Amazon, and big box pharmacies such as CVS Pharmacy to manage the current models of primary and continuing care healthcare systems and corporations. I have included a link to a recent Forbes report that looks at the current cracks in primary and continuing care (Pearl, 2022, https://www.forbes.com/sites/robertpearl/2022/10/10/amazon-cvs-walmart-are-playing-healthcares-long-game/?sh=1f138fa978f6). These models that are vertically integrated, focused on efficiencies, and supporting customer loyalty and professional development may not reflect our Canadian vision of healthcare but they do present uncomfortable options.

The other alternative model to ongoing professional care teams is the Independent Living Centres (https://www.ilc-vac.ca/core-programs) and the Clubhouse (https://clubhousecanada.org/about/) models that provide peer support and peer-directed services in many Canadian cities as part of international movements. These two provided much of my training in peer-run services and they were active in developing both research methods and theoretical models of peer research as part of this book.

There is also growing popularity and effective use of online peer support groups for a range of chronic conditions that range from groups run by professionals, structured peer-led self-management training, peer coaches to online support. In the meantime, projects such as the Wellesley Centre in Toronto, the HIV/ AIDS communities across Canada, and peer research such as PaCER provide examples of how to capture the experience of people in their own voices.

How relevant are these chronic care models to the science of engagement in health research and innovation? From the health system perspective, health professionals are not trained to engage patients in peer support, education, or co-design of programs. The focus of most allied health ventures in peer support includes selecting and training peers to work as assistants to professionals, but it has been hard for professionals to delegate peer support to existing peer support programs that already exist. This is particularly common when working with marginalized populations such as those dealing with addictions, poverty, and mental health issues that have low access to or uptake of health system services.

Peer support programs run by peers are perhaps the best agents of peer research. They understand local community strengths and interests and often take up participatory action research to inform their mission, activities, and advocacy. It would be my hope that funding options for PaCER might be found to provide peer research training for these associations. It is also possible that peer support programs could use the science of engagement to create their own model of peer research.

Recovering

The site of recovering physical and social capacity that has been aligned with physical technology and recent biological engineering.

The recovering ring is similar to the previous one but is about the personal search to find a new normal in everyday life through adapting or regaining everyday skills and relationships. It remains a deficit-based approach that relies on assessing functioning and creating ways to reduce deficits or to re-establish former skills as part of emerging roles and responsibilities. Physical rehabilitation (physiotherapy, occupational rehabilitation, and speech therapy) focus on regaining function and competence. Social rehabilitation considers emotional, cognitive, and social skills. These two approaches are often merged to reduce the lasting impact of illness, accidents, and trauma.

Cancer treatment provides an excellent example. More cancer patients become cancer survivors as new treatments reduce mortality rates. However, the impact of treatments and the fear of recurrence leave many incapacitated. Cancer specialists have created a major psychosocial or rehabilitation response to support survivors. This is significant because this response occurs simultaneously within the medical system (Mikkelsen et al., 2007, https://doi.org/10.1080/02813430802295610) and within community services (e.g., Wellspring Cancer Support, n.d., https://wellspring.ca).

These two service options are significantly different. Psychosocial rehabilitation tends to be funded by the hospital cancer systems and uses professional interventions and health professionals. Community, patient-run options such as Wellspring Cancer Support Alberta (https://wellspring.ca/alberta/) are more aligned with the next two subsystems, community inclusion and peer support. The main difference is funding and costs; formal programs cost more and are government funded, while community supports such as Wellspring rely on fundraising but are less expensive because of the use of volunteers and peer support.

Psychosocial teams, unlike allied health teams, tend to be interdisciplinary, where each professional is more independent because they are less dependent on medical compliance and oversight. Most teams have a common focus (e.g., mental health counselling clinics, physiotherapy clinics, or head injury programs). Their means of funding is variable, including combinations of provincial health, health insurance, health associations, or fee for services. Therapy is more likely to be connected to health funding when they use approved medical protocols. These protocols reinforce status among professionals who may be paid on different scales. There is the risk of creating a ghetto of 'ancillary' professionals not formally recognized who are seen as assistants that are supervised by approved healthcare professionals.

Patient roles reflect their perceived deficits—they work to adapt to each therapist they work with. They speak their language and aspire to the goals of their treatments. Patients often feel anxious about leaving these supportive programs. The role of peer support in many of these programs face similar problems as noted with allied health teams. Peer support tends to be a program, with supporters trained and supervised to act as assistants carrying out program protocols. There is little room for natural peer support, unless connecting with clients is encouraged outside of program activities. In some situations, peer support is discouraged because it may distract patients from the approved—and funded—programs.

Therapy programs are a breeding ground for physical and biological engineering of assistive aids that can be funded by government allocations. The rapidity and scope of the innovations emerging at the intersection of biological and physical functions will be heightened by the addition of new digital technologies, which enable computer-assisted movement and communication. Technologies such as virtual reality and gamification are increasingly used in psychiatric and physical rehabilitation.

My Places and Roles: Community Inclusion

This site focuses on the rights of inclusion and adherence to socially valued roles of work, volunteering, family, and leisure with the aid of adapted routines and technology.

Community inclusion is the first of the systems not controlled or funded by provincial health budgets. Funding is provided by provincial community services, health charities, United Way, and a variety of foundations. The concept of community services began from the early adult training and employment services for the blind after the First World War and the Halifax explosion in 1917. Community inclusion began through the developmental disability family movements of the 1950s. Special schools were established to prevent institutionalization of young children who grew up and into sheltered workshops, to allow people with disabilities to 'go to work.' Early sheltered workshops were soon replaced by training and employment options that taught age-appropriate employment skills. These, and all other community inclusion options, are not considered to be part of the healthcare system, per se, and staff are not considered health professionals.

Community support is considered essential to achieving health for persons living with disabling conditions, including many related to chronic health conditions. Most staff working in this area are trained to support PWLE with a variety of conditions at colleges and universities. In a community-inclusion system, programs specialize in everyday roles and relationships, including those in employment, living together, and integrated social, artistic, and sport opportunities. It is also true that adults in integrated programs find companionship, peer support, and accomplishment. Regardless, staff in this outer ring of systems see themselves as allies in achieving integration and providing support when obstacles arise.

There is a growing movement to support integrated schools, workplaces, and leisure that reduce the stigma and isolation of PWLE. This will be accelerated as technology and assistive and communication devices related to mobility, employment, and living at home become widely available. As the burden of illness and disability is reduced through early intervention and technical adaptations, we will see a dramatic extension of productive life years for everyone. The tenor of community inclusion and support will shift as former clients become employees to meet the projected employment gaps.

My Right to Belong and Contribute as a Citizen

This final ring reflects health supports not part of the official health system that are used by all citizens to achieve good health. This includes technologies available to everyone who can afford them

At this final level, patients are more interested in being able to find supports that everyone uses—activity and heart rhythm technologies, sugar monitors, massage therapy, physiotherapy, a scooter instead of a wheelchair—and as technology improves in mobility and other assistive devices, seniors, patients, and persons with disabilities will continue to be a growing market sector. It is here that the issues of inequity are challenged.

We now come to the end goal of an emancipatory health system from a patient perspective that is grounded in equity, social justice, and emancipation. It is, at this outer ring, that the focus of health shifts from 'cure' and 'fitting in' to the right to belong and thrive because we are enough just as we are. To begin, we must understand how JEDI principles can be embedded in organizations, civic systems and society. The following definition of equity summarizes this final ring of the diagram:

> Equity is fair treatment, access, opportunity, and advancement for all people, while at the same time striving to identify and eliminate barriers that have prevented the full participation of some groups. In order to improve equity, we must increase justice and fairness within the procedures and processes of institutions or systems, as well as their distribution of resources. Tackling equity issues requires an understanding of the root causes of outcome disparities within our society. (Minow, 2021, https://doi.org/10.1162/ajle_a_00019)

It is here that we focus and work toward what an inclusive society might be like. Patients and communities align with innovative consumer services, new political allies, peer support initiatives, and mainstream services. This system, if it is to be called a system, also includes web chat rooms, peer support groups, along with citizen science research and open science. We also find community innovation and social enterprises being led by citizens and PWLE.

At this final stage we return to an early pioneer in this work of justice through inclusion, the international Clubhouse movement that grew from the Fountain House movement in the late 1940s by a group of six patients who met in an institution to share stories and find new ways to deal with the challenges of discharge. They knew that they needed to find housing, meaningful work and relationships and ways to handle the challenges of fluctuating mental

health. Today Clubhouse is still a social enterprise (Clubhouse International, n.d., https://clubhouse-intl.org/what-we-do/overview/) that has created an alternative to psychosocial rehabilitation clinics and programs. The success of Clubhouse has replaced many psychosocial and community inclusion mental health programs, and, in many jurisdictions internationally, these peer support programs receive government funding to promote community inclusion. Like most health-based social innovations, Clubhouse changed as health dollars were funneled to these effective recovery membership centres. With the legitimization of funding, Clubhouse became a sought-after employment option for mental health professionals.

Many new social movements operate in this space. They are strengths based, building patient and PWLE capacity to take up work, the arts, sports, and peer support using their skills and talents. These programs are natural sites for collective action, capacity building, and problem-solving.

Voices of Men (http://www.voicesofmen.org) is a one-man show that performs for mixed gender and single-sex groups as part of the men's social movement to reduce sexual assault, domestic violence, and sexual harassment. It uses humour and male celebrity voices to show that men can be both part of the problem and part of the solution.

A social movement called The Phoenix (https://thephoenix.org/movement), started by Ashoka Fellow Scott Strode, is a national network of volunteer-led programs battling isolation. Participating in The Phoenix's activities, from rock climbing to yoga, gives individuals activities to occupy their time and achievements to help those fighting addictions build a sense of themselves as capable and strong. This constitutes a psychological bedrock and a new community, which helps build lasting recovery.

Disability and mental health, aging and Indigenous studies were the first health-related groups to evolve through the above continuum from conventional healthcare, psychosocial and community inclusion. They were also the first to move toward peer and membership-based support. It is no longer an issue of 'fitting in' but the right to belong. If we focus on fitting in, the emphasis is on the deficits of the person who must be trained to be more 'normal.' The right to belong asserts that everyone has the right to be a member of society, and the focus is on making society accessible and inclusive.

University programs that promote emancipatory social science align with a social ecology based on JEDI principles and the study of systemic discrimination. Ashoka changemaking is a major contributor to this space, using academic resources and changemaking fellows to work with communities to co-design and implement social enterprise. Universities, schools, and community action groups that support emancipatory social research involve groups in analyzing their own challenges in order to confront sources of long held marginalization.

This space is more than a site of innovation and social rights. As a site for social enterprise, it has the potential to address the major obstacle to community development—how to pay for the innovative services developed. It is here that I introduce an alternative to grants. It is individualized funding through service brokerage that puts funds in the hands of families and patients to purchase the services and supports they need. Without a monetary system such as this, which is currently evident in assured incomes for veterans, persons with significant disabilities, and handicapped children's allowances, there will continue to be a charity ethic to promote the right to live in the community. Without the right to purchase and evaluate needed services, there is no equity. In completing this section, I acknowledge that the Independent Living Resource Centre of Calgary that took me in and helped me understand the essential difference between the support of a consumer led community and the role of professionals in changing the direction of my commitment to social justice and inclusion.

An Example of How the Above Health System Tool Might Play Out for Seniors

This example is informed by *Grey Matters* data, building on research done with participating systems that seniors use.

Geriatrics level is informed by the science of aging as the biomedical treatment of conditions related to aging. It is the practice related to biological decline, with treatment being informed by biological markers. For example, a study of resilience might look for resilience genes, or how people who are resilient are different from those who are not, according to some characteristics like adrenal functioning, health status, or depression. The language deals with slowing loss or decline and is home to metaphors such as 'the grey tsunami.' Some refer to this domain as reverse development, as assessments use age markers. While essential, many seniors feel defined by the degree of loss.

Recovery, psychosocial, or gerontological level of healthcare and research is devoted to 'reducing the problems of aging,' and tends to be found mostly in professions such as social work, nursing, rehabilitation, and psychology. Gerontology is the scientific study of the bio-psychosocial phenomena associated with old age and aging. These professions bring their disciplinary gaze to seniors' experiences so that professionals and policymakers can be more effective in providing services and policies. Gerontology research also uses patient-reported experience measures (PREMs) and patient-oriented research (POR) and standardized data measures as well as qualitative research to describe common reactions to the aging process. Seniors who come into contract with psychosocial rehabilitation learn to see themselves through the lens of the therapists they are referred to. These therapists not only provide adaptations, they are also

the gatekeepers to needed assistive devices. Most seniors learn quickly to work within the boundaries of the therapy and to compartmentalize their lives to fit.

My place, community inclusion, focuses on aging studies, which is a relatively new field. This emerging field of study is related to healthy aging and was the foundation for the *Grey Matters* project. Here, the focus shifts to tapping into the expertise of seniors (values, beliefs, language, media) and the politics of aging. In many ways, this new area is like women's and disability studies, although the academic roles of seniors have yet to be widely accepted in universities.

This research is closest to the interests of seniors. It clearly states that aging is not an illness or disability, nor is it a problem. Aging happens to everyone, and, like any other stage of life, becoming older has advantages as well as challenges. Aging studies would place the 'problem' not with individuals but with society that tends to use age as an excuse to marginalize older people because they are seen as being less productive once they reach 'a certain age.' With the loss of status and place in their communities, seniors often lose connections, struggle on fixed incomes, and become overwhelmed with the illnesses of idleness.

Patient experience in aging studies is considered from a patient perspective and joins a host of other traditions including health professionals who write as autobiographical ethnographers about their experience as patients. COVID-19 has brought awareness to the systemic discrimination of seniors who live in congregate care. It was interesting that the battle cry came not from seniors' advocacy groups but from medical staff and researchers. There is a long way to go, beginning with changes in each of the levels within the systems as seen by patients.

The focus on critical theory and social justice fuels the last level in seniors' health systems.

My right to belong is represented by seniors' advocacy, action groups, and peer support that includes the adoption of universal design and mainstream services. The normalization of accessible architecture and assistive devices (designer scooters and easy to use kitchen utensils) that are used by everyone was the motivation behind the *Grey Matters* research on resilience and demonstrates that seniors can be agents of their own lives and support the lives of others.

It is now easier to identify problems faced by patients and PWLE in achieving the roles they aspire to and the relationships that may promote or constrain these aspirations. Dramatic changes in professional roles are possible when, as a group, they decide to adopt other ways of working that promote confidence and personal agency in those they serve.

You are invited to create the template in your area of research or practice, and to use this to consider potential ways of increasing patient involvement

with their own health and healthcare. This understanding of current and potential roles will help define the patient experience research needed to be done.

In the last few years I have been privileged to be part of a family initiative to support the 96 year old matriarch to stay at home and take part in all decisions about care, travel, meals, engagement. To facilitate this, the daughter devised a data system to focus on the many co-morbidities so that everyone, contributed to record data and discuss this openly in house and with her input and with her doctor. It was a privilege to see what a beautiful life and death could be when her role was to be heard and loved.

An Example of a Social Enterprise That Aims to Promote 'My Right to Belong and Contribute'

One of the best-known social enterprises in the UK, Greenbank College (https://www.greenbankcollege.org.uk), began as a challenge to existing health-based institutional services for physically disabled youth in Liverpool. The existing system consisted of an institutional residence built for polio survivors, nurse-run group homes, and education provided through the institution. Decisions about treatment and future occupations were made by staff. It was a benign system that socialized young people to become patients dependent upon the healthcare system when they grew up.

Gerry Kinsella, a polio survivor and the founder of Greenbank, led a campaign to raise funds to buy the original institution and started a college with apprentice-style training and employment options. He received European Union funding and began to expand in direct competition to sheltered workshops. I spent time at Greenbank as part of a study of social innovation, and together we studied the programs—a prosperous training college, an athletic wheelchair company for competitive sports, a competitive recreation program, and a whole food restaurant. They had, in effect, created a parallel system to the expected health system for physically disabled youth. The following is a sample of the roles and relationships within the system of Greenbank projects above.

Others control my health—diagnosis and treatment: past places included institutions, group homes, workshops, and nursing and home care routines. The 'patient' experiences were marked by negative self-concept and excessive external control by care staff and systems. The data captured themes of vulnerability, fallibility, risk, protection, control, anger, and despair.

My place—community inclusion: The Greenbank site included a variety of training programs. Experience here was identified by concepts such as accepting, curiosity, self-help, receptiveness, and affection. Experience was marked by a positive self-image, with positive external support of peers. The themes spoke of exploring, 'give it a go,' and peer support that created new roles as students, learners, risk takers, and part of the peer community.

My right to belong: Smithdown was the mainstream competitive business site. It included the wheelchair manufacturing company, a whole food restaurant, and a consignment store. The experiences were clearly identified—competent, independent, willing to risk. The new environment and expectations created new roles as citizens and employees

Research Potential of Systems from a Patient Perspective

This last section suggests some research methods not covered in sections one and two that are more appropriate for research focused on making a difference within health systems. They relate more to the need to identify and explain systems blockages and understanding patient experience from their perspective. These systems and related methods will be integrated in the research options in Chapter 11 that combine the methods from Sections 1 and 2 with new work to prepare to bridge between academic research and design thinking of social innovation and social enterprise.

Crowdsourcing

As health research adopts citizen science as a bridge between academic research and social innovation/enterprise, online research options such as crowdsourcing reinforce the needed ability to reach diverse populations to address JEDI requirements in specific health systems. The first round of research might include the request to identify the health systems or services that a specific population uses, and these could be plotted on a system template, as presented in this chapter. A template that reflects the health use or lack of access could then be sent back to the online participants with options to include stories about the systems that work well, why the systems are used, and stories about the gaps, conflicts, and lack of access. A third round of online crowdsourcing might select several systems and ask participants to vote for the one that should be addressed first in research. From there, crowdsourcing could build on the existing online populations to conduct more detailed research.

Narrative Analysis

Narrative methods have been used in peer research to solicit stories of personal experiences in health systems as part of research to explain the blockages in these systems from a patient perspective. We now extend this to discussing how peer research might inform social innovation to resolve or reframe existing problems in health systems. In looking back over the reports and projects in the PaCER PRISM hub, I was surprised to see how many of the suggestions

related directly to systems blockages and the subsequent creation of new roles, relationships, and programs.

The process of identifying blockages begins with co-design, where the main concerns of patients are identified from a number of perspectives using online and in-person consulting as in the following examples.

- In a recent research internship related to young people with inflammatory bowel disease, two teams came up with topics related to their relationships with food. The group identified an interesting finding. Patients initially were looking for professional support in managing unpredictable reactions to food. After conducting their study, they had a new understanding of the blocks in the system and patient experience. They realized that it was important for patients to find their own way to develop a healthy relationship with food. They suggested that professionals needed to support patients after diagnosis and provide resources for how patients manage their food through unpredictable reactions, changes in diet, and family traditions. This required a mixture of patient expertise and professional support.
- In an early study that was to identify appropriate wait times for hip surgery, peer research discovered that patients were most interested in what they could do while waiting for surgery, in order to be prepared. Their research identified serious system blockages, which included unnecessary appointments that took many months to sort out and the lack of information about what they could do to prepare for successful surgery and recovery. Their experience before surgery was a mix of frustrating appointments that did not prepare for surgery and a lack of ideas for exercise, diet, and reading. Their research had a major impact on subsequent tools to prepare for surgery, driven by patient input and analysis.

Discourse Analysis of Systems

Discourse analysis is likely the most effective tool in social innovation because it lays bare the obstacles to emancipation and progress through the language used by those in power. Those who struggle for power study the language of those in power, while those in power seem unaware of the impact of the language they use (McCauley, 2013). Relational-cultural theory provides a theory base to using groups to build strong motivation for action.

Discourse analysis can be part of co-design or data analysis. Online resources are ideal for this work because they are the forward-facing representation of systems that describe the services and programs provided. The following is

a simplified discourse analysis process that quickly identifies distinctions between different systems in the concentric circles, which can be done by students or peer researchers:

- Who is the author and what is their relationship to the reader or the patient? For example, what authority or power is in play:
    - Expert, colleague, victim, ally/advocate, scientist, professional, program director

- Language cues that identify power imbalances
    - Pronouns: Who is the 'I,' 'she,' 'we?' Identify if the patient is being acted upon—'me,' 'her,' 'them'—or is an agent— 'I,' 'we,' 'they.'
    - Verbs: Are there signs of patients deciding, acting, and making progress, or are the verbs a sign of being acted upon?
    - General tone of language: Identify the type of language being used. Is it professional language, colloquial or collective language, or inspirational and goal-focused language?

- From the above, you can identify roles in the text, what is expected of each, what is the power balance, what happens if the patient doesn't play the roles expected, and what does the person gain from playing this role.

Summary

This chapter looked at health systems from a patient perspective to uncover obstacles within the current system. We introduced a patient perspective of a health system that incorporates not only funded and established illness care, but a continuum of care that includes wellness and equity. This is important because of JEDI principles of diversity and inclusion that underlies the systemic barriers to culturally and population-based care.

This made it possible to consider the forces of innovation and how they relate to a patient and community view of health and health equity as a foundation for making changes in our current healthcare systems. In this chapter, we also begin to introduce new research methods that can build patient and community awareness of the tools of innovation that are designed with them in mind. These will be presented in the following chapters.

Questions for Discussion

1. Where did you find yourself on the systems maps introduced in this chapter?
2. How would the templates work as part of your research or peer support work?

Resources

Use of Discourse Analysis to Understand Different Healthcare Options for Moral Injury

The following is a group process designed to teach systems analysis using the template and a simple group casebook in an undergraduate course in innovation in health research. Each person chooses a subsystem from the template, locates a website or document about that subsystem, and then uses a simplified discourse analysis to identify roles of patients and professionals that identify identity and agency (power and making decisions).

One of the students in the course agreed to share her work. One aspect of the case study is included in each of the chapters in Section 3.

Table 9.1 *Innovations in Health Casebook*

Innovations in Health Casebook

Systems thinking and discourse analysis

This assignment begins with three analyses using new and adapted theories related to patient experience and design thinking:

1. Systemic analysis of patient and disability roles in health and wellness systems.
2. Salutogenesis, building patient expertise and resilience in health through understanding patient experience.
3. Standpoint theory, building capacity for changing patient roles and then pivoting to more creative work, based on the first three days of analysis.
4. Choosing a social innovation using information science options that will empower patients.
5. Preparing a protocol for a low-risk innovation protocol.

Health systems: patient and disability roles and agency
Resources: Greenbank website and articles, peer research example, systems theory

The first framework that influenced the design of my moral injury social innovation was using a discourse analysis to understand how systems and institutions, defined as a collection of shared understandings that constrain and prescribe actions, impact the presence of moral injury. Viewing systems from a patient perspective revealed weaknesses of the traditional treatment and diagnosis system that prevented patients from becoming well. It also prevented healthcare professionals from fulfilling their duties, while revealing the elements of community inclusion and peer and natural support systems that support patients in their journey to well-being.

See below for a demonstration of discourse analysis for the three systems introduced above.

Table 9.2 *Treatment and Diagnosis Analysis*

Data: Treatment and diagnosis (Nuckols, n.d., https://www.naadac.org/assets/2416/cardwell_nuckols_treatingmoral.pdf)	**Analysis**
"If one cannot accommodate or assimilate the event within existing schemas about self and others, guilt will be experienced, as well as shame and anxiety about the personal consequences."	The patient is to blame for their inability to assimilate the morally injurious event.
"Shame is associated with a wide variety of psychological problems, including depression and PTSD, as well as physiological changes including an increase in harmful cytokines and proteins that promote inflammation and cortisol."	The patient is something to be studied rather than a whole person—their actions are not a natural reaction to a personally horrifying event, but a chemical consequence of shame.
Professionals must "develop a knowledge of the exact nature, conditions, issues, environment, locations of the veteran's theatre of operation."	Professionals are responsible for knowing every minute detail of the morally injurious event.
Summary: The presentation is written for professionals, not patients. The patient is unconsciously at fault for their illness and professionals change the way they view the morally injurious event, so that shame and maladaptive coping strategies lessen or cease. Treatment cannot happen unless the patient wants to engage with the professional, and it is the professional who decides when amends to the morally injurious act are too much. The professional is active while the patient is passive, within the article.	

Table 9.3 *Peer and Natural Support Analysis*

Data: Peer and natural support ***Project Trauma Support*** https://projecttraumasupport.com/	**Analysis**
"The purpose of the groups are not to exchange war stories, so details of traumatic incidents are not shared. Instead, the meetings are intended to help members weave a new story of hope and healing."	Members of the group assist each other in creating new narratives. Power is horizontal rather than vertical.
"For me, the peer support group is a safe place I can go once a week and be with other first responders who truly understand what I'm going through. I can be honest and not feel judged. I can shed a tear and not feel weak."	Members feel empowered by the group; there is no fear of shame or pressure to share every detail of their morally injurious event. They remain in control.
Summary: Those who are a part of the group are seen by peers as warriors. By taking the initiative to attend meetings, the individual is doing something that their peers consider to be good, and they can actively help others who are experiencing a similar injury. The role of each member is to support others.	

My involvement with health systems began with large institutions for mental health and disabilities. These removed citizens that made the general population uncomfortable by claiming to care for their needs. I learned quickly about the dominance of hierarchy within these settings that extended not only to staff but stigmatization of patients. As an academic, I worked to understand how systems created restrictions for those they served, with seniors in long-term care, disabled citizens in community workshops, and profoundly handicapped children and youth in custodial institutions.

I also worked to create new systems that tried to reverse restrictions on the following: legal guardianship; communications technology for disabled persons; new community mental health options in Russia and North America, including Mexico; independent living in England and Canada; professional curriculums for teachers of profoundly handicapped and community disability studies; and community mental health workers.

As an academic, I studied systems from the perspective of an upstart social justice program that seemed destined to challenge established practices, and through all of this I became convinced of the following findings.

Findings

In the deficit-based diagnosis and treatment system, the patient is passive and responsible for changing their worldview to correct the deficit. This is guided by a professional who decides when acts of making amends are sufficient or insufficient, thus decreasing the patient's agency. The relationship dynamic is about conformity with the professionals deciding when the patient graduates from being ill to not ill.

The example of a community inclusion system, the Whole Health Medicine Institute, acts against the hegemonic medical system by training healthcare providers to understand health holistically. Healthcare providers enrolled in the Institute have more agency than patients in the treatment and diagnosis system but are still acted upon by the program. To be successfully treated, one must adopt the ethos of the program.

Supporting others can facilitate new self-narratives. The peer support system changes the role of patients from morally corrupt individuals to people who can help others and make meaning out of their experiences. Peers understand the unique factors that lead to moral transgressions and create a non-judgmental environment through which parties can redefine themselves. Power is horizontal rather than vertical, and the dynamic is one of relationships and learning.

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