White Paper

Person-Centred Care Systems:
From Theory to Practice

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ISQua | International Society for Quality in Health Care

Foreword

With great pleasure, ISQua publishes this White Paper on Person-Centred Care.

Person-centred care is not a new idea. The authors of this paper found it mentioned in publications as far back as 1934. Healthcare professionals would agree that they are person-centred; that their mission – their core business – has always been to help their patients.

Hippocrates is quoted as having said, "Cure sometimes, treat often, comfort always." This emphasizes the belief that what the physician deals with is not a disease but a person. This was said in a time when a cure was not the expected outcome of what a doctor had to offer. As the ability to cure increased dramatically, the focus shifted toward the disease. Health care professionals became specialists, eventually superspecialists, perhaps most manifestly seen among physicians, but certainly not only here. This added enormous value to what healthcare had to offer, but other values were lost in the transition. Physicians became problem solvers and fixers. The core question when meeting a patient would be "What is the matter?" followed by "What can we do to fix it?".

Patients and families began to raise their voices to call for something more. To not 'throw out the baby with the bathwater'. After all, technical expertise is needed, but it is not enough. Healthcare professionals should appreciate that their task is to help a person. This is expressed in the question "What matters to you?" followed by "How can we help you achieve this?"

What will it take to be able to provide genuine person-centred care?

The authors of this paper have come together from across the world, some from a background as patients or advocates, others from a background as healthcare professionals, united by the desire to help healthcare professionals and policymakers answer this question. Their outset is summarised in four guiding questions:

- Why is person-centred care so difficult?
- What is person-centred care?
- What are the implications of person-centred care?
- How do we make person-centred care the norm?

They do not conceal that it is not just a question of adding a touch of person-centredness to business as usual. To quote from the Executive Summary:

"To make person-centred care the norm, there is a need to systematically redesign legislation, organization, funding, information systems, education, and research. The aim is to design person-centred care into the system so that person-centred care is the logical choice and is expected and rewarded."

We hope that this White Paper will guide this redesign. On the other hand, those healthcare professionals who are not content with waiting for the entire system to be redesigned will also be able to use the White Paper as a starting point for their own journey toward person-centredness.

Finally, on behalf of ISQua, I want to thank everyone who has spent time and effort making this White Paper a reality. The diversity of voices that have contributed is one of the many things that makes this paper unique.

Dr Carsten Engel

ISQua CEO

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Table of Abbreviations

CAS	Complex Adaptive System
COPD	Chronic Obstructive Pulmonary Disease
EBM	Evidence-Based Medicine
EHR	Electronic Health Record
EU	European Union
ICT	Information and Communication Technology
IHI	Institute for Healthcare Improvement
ISQua	International Society for Quality in Health Care
PCC	Patient Centred Care
PJ	Patient Journey
USA	United States of America
WMTY	What Matters To You?
WHO	World Health Organization

Executive summary

Modern medicine achieves outstanding results and is a huge success. However, both patients and health professionals have repeatedly voiced a vital concern: health care is currently not paying sufficient respect to the individuality and human dignity of persons who seek help from care systems. PCC calls for a stronger focus on and collaboration with the persons seeking care.

PCC care is a sharing of power to ensure that the answer to: "What matters to you?" drives care decisions. Patients and professionals work together, within the constraints set by the care system, in a care process to achieve goals that are meaningful to the person.

The person is an individual with an identity, a history, a cultural and personal background. The patient is a secondary role the person takes on each time they interact with health care. Likewise, professionals are persons first and take on the role of their profession second. PCC builds on the recognition of both patients and professionals as humans first.

To make PCC the norm, there is a need to systematically redesign legislation, organization, funding, information systems, education, and research. The aim is to design PCC into the system so that PCC is the logical choice and is expected and rewarded.

In a system of multiple self-regulated agents, the tools for change include:

- Changing the system's goal from diagnosis centred, episodic and reactive care to person-centred, integrated and pro-active care.

- Educating professionals ⇒ making it both safe, expected and easy to tailor evidence-based care to the person's needs, values and preferences.

- A new information flow ⇒ make "what matters" to the patient the goal of care and create an information flow that shows how care decisions in the patient journey are linked to the goal. Evaluations that provide system feedback on the impact on patient defined goals.

- Align the system structures to the new PCC logic: Check that incentives reward PCC, that legislation allows information flow along the patient journey,

that information systems support the patient goals, the seamless patient journey and proactive management of risk, and that organizations are encouraged to work together to reach patient goals.

Care professionals are "visitors" in the patient's life. The patient is the host, guide, and enabler of the healing journey. The care system's goal is to enable the person to thrive in their life with as little support from health care as possible.

Chapter 1 – A white paper on Person-centered Care (PCC) – why?

Modern medicine achieves outstanding results and is a huge success. We know more about improving both individual and population health than ever before. However, as we witness these giant steps forward, both patients and health professionals have repeatedly voiced a vital concern: **Health care is not paying sufficient respect to the individuality and human dignity of <u>persons</u> who seek help from care systems**. PCC calls for a stronger focus on and collaboration with the patient.

The call for PCC is not new. Already in 1934, Gordon wrote:

> *"...what else could a patient be but a person? The answer is that in the progress of our art the case of illness may, by almost imperceptible stages pass, from being a person through the stage of being a problem and end in being regarded as so much material. [2]*

Many voices across time, geography, and culture document the need for PCC [3–7]. There are many published descriptions of why PCC is important and what PCC is [8–13]. Numerous well-designed interventions have been trialled to improve PCC [14–18].

Yet, patients still regularly report care that does not answer their perceived needs and may even be experienced as harmful and traumatic [19–27]. Mr Porter's story below provides a distressing example:

> *Mr Porter, a paediatrician, suffered a spinal cord injury in 2009. While he was in the hospital for this injury, he experienced the following:*
>
> *"Stopping at my room, I could hear the voice of the Head Nurse with another voice. The next moment I felt pain on my head as the bandage was truly ripped off the back of my scalp, and I heard a voice say, "OK, we'll look at it again next week."*
>
> *And silence. I turned the wheelchair around; no one was there.... Spectacular 21st-century technology had truly saved my life, but on the other hand, communication between the patient and the doctor fell so low, that the doctor did not even feel that he had to come around to the front of my wheelchair and say, 'Good morning, how are you? I've come to look at the sore on the back of your head.'"*
>
> *(personal communication, Israel)*

The call for PCC continues to come directly from patients (https://patientrevolution.org/story-library), from international health management organizations such as WHO [28], the Institute of Medicine in the USA [29], the EU [30], from professional

voices [31], researchers [32] and of course from patient advocate organizations (Beryl institute, Planetree, Picker Institute, The Patient Revolution).

Our Aim:

This work was initiated by ISQua, who assembled a group of patient representatives across four continents and challenged us, as both patients and professionals, to take PCC one step further.

The dual goal of this white paper is to contribute to a new understanding of what PCC is and contribute to making PCC a system characteristic of care systems all over the globe.

Our Process:

Unlike other work on PCC, which mainly originate from western contexts, this document started its development in an international group of patients, professionals, and researchers with relevant life and professional experience with PCC—and the lack of PCC. We come from African, European, South and North American, Middle Eastern, and Asian backgrounds. Despite such diverse settings, our shared stories and experiences connect as a solid foundation for common answers to these guiding questions:

* Why is PCC so difficult?
* What is PCC?
* What are the implications of PCC?
* How do we make PCC the norm?

Chapter 2 – Why is PCC so difficult?

A patient identifies a person receiving care from a healthcare service. Every patient is, first and foremost, a person. A patient does not stop being a person with an identity when they become a patient. "Patient" is a role that persons have from time to time. We will try to keep the terms "person" and "patient" apart, as the first pertains to the whole individual, with an identity, a history, a cultural and personal background. The second, the patient, is a role persons take on each time they interact with health care.

Patient empowerment has come to be a key term in PCC literature [33]. When used, it signifies system or professional support to patients in *"…a process through which people gain greater control over decisions and actions affecting their health"* [33]. An empowered patient feels both well-informed and entitled to take action and contribute to their care. As such, the empowered patient is a pre-requisite for PCC.

However, patients are persons who are already powerful and autonomous in their own lives. No one would think to "empower" a customer in a grocery store. The term "patient empowerment" indicates that the person is dis-empowered when they become a patient. The power imbalances between patients and care professionals are at the core of the call for PCC.

Ignoring the person who is also a patient:

The following phenomena, often working together in concert, are thought to facilitate the distancing that allows the professional to "ignore the person" and disempower the person when they are patients.

Depersonalization:

The de-personalization is enabled by the quartet of 1) De-individuation: the process of disregarding or even erasing individual traits or symbols of identity, such as name, appearance, personal history, etc. 2) Denial of agency: Someone who is prevented from acting, such as ill persons often are, become less able to assert, underline and express their individuality. 3) Dissimilarity: Common ground is not apparent when another's lifeworld is so different from one's own. 4) Confusing the patient role with the person's identity. Personal and cultural background shapes people's understanding of the patient role. How a person acts in a patient role may differ substantially from how the person acts outside of a health care context.

This quartet pushes the unaware professional towards an implicit perception of the patient as someone who belongs to a group of "others" instead of belonging to "me and mine."

Bracketing of the person

While professionals are well aware of the inseparable nature of person and body, in diagnosing or deciding on treatment for a health challenge, the professional focus may move away from the person who lives in the body. While "problem-solving" is ongoing, the personal relationship may be neglected, as these processes are thought to be in cognitive competition. Professionals may not be able to perform complex problem-solving and continue an empathic interaction with the patient simultaneously [34] [35].

While the professional focuses on "biology," a fundamental shift occurs in the relationship between these two humans: The professional, another person, takes on the role of content expert. The person in the patient becomes invisible and loses their relevance to the situation at hand. The human body becomes the substrate for professional work. The person is "bracketed" for a while.

Patients both recognize and tolerate this "bracketing" when it happens as part of an acknowledged and mutual understanding of the necessity to shift focus for a time. As long as the professional honours and recognizes the person, both before and after their focus shift to biological/ condition issues, all is well. The patient is usually appreciative of the necessity to focus on one thing at a time and realizes that this may be in their own best interest.

However, by not greeting Mr Porter, the physician effectively reduces Mr Porter to merely a body. Mr Porter's right to self-direction is overruled, and Mr Porter's identity as a person is not only threatened, it is momentarily erased. Mr Porter is treated as if he were a "thing" without personal needs for recognition, support, information, and involvement. There is no "start" nor "stop" to the bracketing.

Standardization and productization:

Evidence-based guidelines and standardized care pathways are beneficial tools that help clinicians ensure technical care quality. However, evidence-based medicine (EBM) was never meant to pave the way for "cookbook medicine." EBM always intended the conscientious, explicit, and judicious use of current best evidence from research and clinical experience to be integrated with a person's needs, values and preferences as they arise from the health challenge [36]. Without concomitant tailoring to the person, a strong focus on compliance with guidelines and pathways turns care into more of a transaction than a relationship, denying personhood to both patient and professional.

Empathy and compassion fatigue – the vulnerable professional:

Becoming overwhelmed and unable to remain close to a person's suffering can interfere with care. The person, who is also a professional, may cope with this painful experience by creating a mental distance between oneself and the subject, thereby implicitly disregarding the patient's personal needs. The result is an interaction that is emotionally stunted. Resistance to becoming vulnerable by professional persons is part of the challenge. Authentic relationships between persons involve being open to the other. Role or task definitions created without reference to the underlying person, in both the professional and the person, contribute to these confusions.

Vulnerable and marginalized populations

It is estimated that by 2030 up to two-thirds of the world's poorest population will be living in settings of fragility, conflict, and violence. (FCVs) [37]. Marginalized and vulnerable populations such as low-income and uninsured patients, immigrants, and minorities due to ethnicity, disability, sexual orientation, or age are typically underserved by social and care systems. Often environmental challenges, such as unsafe and unstable housing, unhealthy environments, and lack of basic needs such as food, shelter, and clothing, exert a disproportionally high disease burden. Paradoxically, these populations who most need care experience more significant barriers in accessing care than "normal patients" due to systematic discrimination of persons with lower health literacy, disabilities, and less available social and physical resources in their network.

For individuals in minority and low-income groups, a pervasive mistrust of the healthcare system compounds the situation. A history of trauma sensitizes the person even more to inhumane or mechanical care [38]. Persons who sense bias or being "talked down to" experience mistrust and exclusion from decisions relevant to their bodies and health.

The consequences of "loss of personhood."

The phenomena that enable "disregard of the person" are complex, as they occur alone or in concert. Their effects, though perhaps unintended and even undetected, are still detrimental. The experience of being rendered invisible and irrelevant to decisions that touch upon one's health and body is experienced as disturbing and problematic by most humans. Research shows that even slight disregard for the person and their identity has detrimental effects on humans: it permits subtle forms of bullying, harassment, and social rejection [34, 39]. Victims report confusion, betrayal, and humiliation [39]. The causes of a mechanical and depersonalized care system are independent of low and high-resource settings, whether in a social

context of conflict or peace. However, the harms may be worse in the social context of conflict and poverty.

Ignoring the person violates the ethical principle of autonomy, yet it is often "forgiven" because of one or more of the following circumstances: The professional has a benevolent purpose and a genuine wish to help. The patient has voluntarily subjected themself to a professional biomedical examination and may consider the biological focus to be expected. The patient generously concedes that the de-personalization side-effect was unintended. The de-personalization is brief or has little impact on the patient's life. The patient is mentally and physically vulnerable with no resources to object. The patient is dependent on the professional and feels that speaking up may jeopardize care quality. Both the patient and the professional find themselves in a system environment where depersonalization has been normalized.

Even though professionals are regularly forgiven for ignoring the person in the patient, this does not make it less wrong, and does not remove the suffering it may cause:

> "Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in a medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself." [40]

Professionals also suffer dehumanization when forced to fit into systems that discourage natural empathy and engagement with patients, engendering the same negative emotions and guilt and shame. The concept of the impartial professional who executes guideline-based diagnosis and treatment may be as important to question and neutralize as depersonalization of the patient [41].

Every system is perfectly designed to get the results it gets

There is no single activity, element, or "silver bullet" that will solve the challenge of PCC because the nature of the problem can not be reduced to a simple "cause and effect" challenge. Understanding how to change first requires understanding why change has not materialized before and learning from previous efforts.

The health professional's dilemma

When asked why there is an inconsistent delivery of PCC, professionals point to a lack of time and competing and conflicting pressures to deliver care according

to professional standards and employer and system regulations. In current care systems, the system logic is focused on offering the most beneficial care available and applicable to the case in front of them, as judged by professional standards. Results are judged by hard outcome measures that are easy to measure and interpret, such as rates of post-operative infections, mortality, and disease recurrence. Evidence-based guidelines are admirable tools and will continue to be so in a PCC system. However, their proper application is to serve as guides supporting patient values, needs, and preferences, not as an end in themselves.

The reality of Mr Porter's consultation was not a meeting between three individuals: the patient, the nurse, and the doctor. It was a patient–system meeting where the doctor and the nurse represented the care system. In the patient–system meeting, the individual professional has limited freedom to invent their own rules of engagement. Instead, the rationale and logic of the system direct the behaviour of the professionals in concert with their professional training and personal beliefs and values.
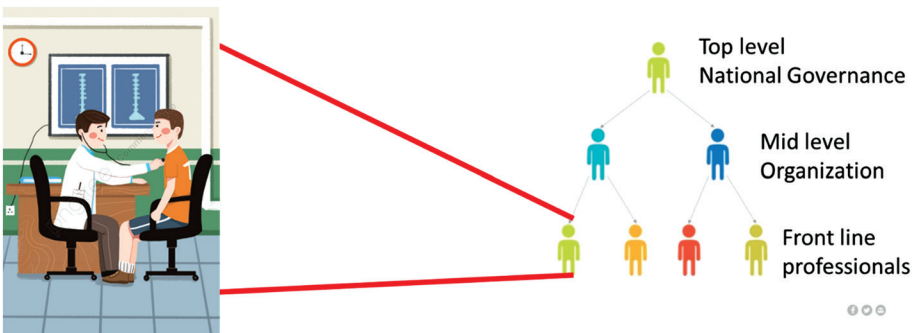
Figure 1: Patient-System Meeting

The system expects the physician to prioritize patients with urgent needs over those with issues "that can wait," such as Mr Porter's challenge. Clinicians are to deliver satisfactory quality care to all patients within the day's working hours. If there is a choice, choose treatments and procedures that provide equal benefit for the least cost. The professional-system perspective may be that there is little room for the PCC approach. PCC is perceived as cumbersome, time-consuming, and potentially risky. Allowing the patient to decide might even lead professionals to take responsibility for decisions with which they are uncomfortable [42, 43]. While all patients want to be treated respectfully and have "What matters" considered, it might be difficult for professionals to gauge how much power and responsibility the patient wishes to assume. Current care models base their quality-of-care assessments on technical quality, not patient-experienced quality. Patient needs, values and preferences are difficult to elicit and may include wishes that the professional has no expertise nor power to solve. In short, from the system perspective, patient defined goals can be described as soft, irrelevant, ill-defined, resource-consuming distractions.

With this mindset as a backdrop to the patient-system meeting, the clinician will disregard their inclination to act as a fellow human being and often honour system priorities before looking at patient priorities. After the system requirements have been fulfilled, the professional will attend to "niceties" such as PCC if the time, inclination, and resources are available.

When experiences like that of Mr Porter become common and even normalized, this can only be described as a system feature. A systematic focus on disease/ condition/ malfunction and professional skills, rather than on the health and lived experience of both patient and professional persons, promotes a paternalistic approach that is distressing and painful. The system fails to create the necessary expectations, support, and training to ensure that all humans, both patients, and professionals, are treated as persons first. The system puts the autonomy of the patient at risk.

What is the current system designed to do?

To make a change, it is central to understand the current health care system's design and how it comes to produce its non-PCC events. We will use tools from "systems thinking" [1, 44] to structure our description of health care systems.

"The Iceberg Model argues that events and patterns (which we can observe) are caused by systemic structures and mental models, which are often hidden. Systemic structures are the organizational hierarchy; social hierarchy; interrelationships; rules and procedures; authorities and approval levels; process flows and routes; incentives,

Figure 2: The Iceberg Model, from [1]

*compensation, goals, and metrics; attitudes; reactions and the incentives and fears that cause them; corporate culture; feedback loops and delays in the system dynamics; and underlying forces that exist in an organization. Behaviors derive from these structures, which are (in turn) established due to mental models or **paradigms**." [1]*

The visible events – the roles in the care process

The visible core events and event patterns in care systems are the health care consultations, which are created through the interactions among three roles:

- The person who requests help to improve or maintain the health from a professional. (Fig 3 – blue line)
- The professional who represents the health care system (Fig 3 – red line)
- The system/ payer, an invisible but omnipresent third partner, who funds and hosts the care process and indirectly regulates the professional

The care process consists of a series of patient-system meetings. The desired outcome (goal) of the care process, and therefore also the design of the process, differs by the perspective of each role. The high-level desired outcomes are well described in many strategy documents, many of which build on the **Quadruple Aim,** which outlines the most important outcomes for each of the three roles: For the patient: patient experience and health and function, for the professionals: The professional experience and satisfaction, and for the system/ payer: cost-benefit [45, 46]
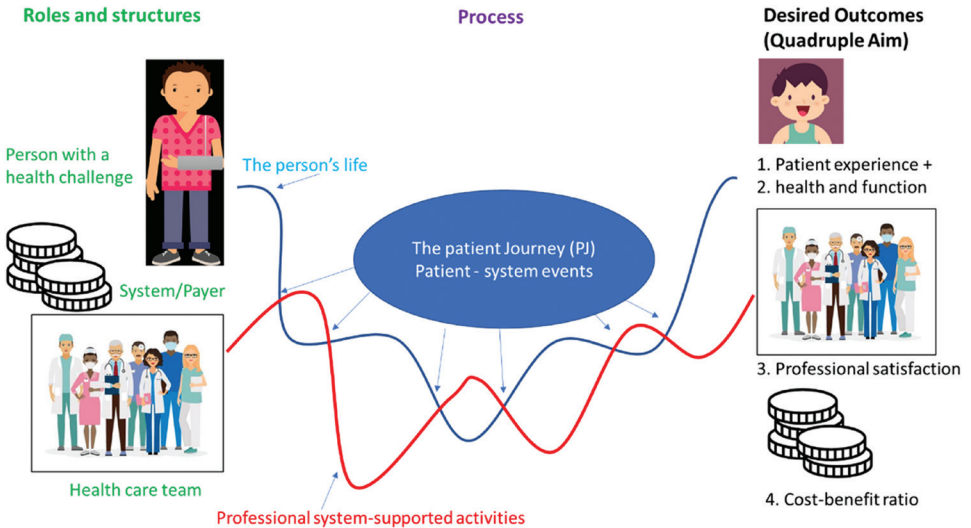
Figure 3: The visible events of the health care system: The patient journey (PJ) arises at the intersections between the professionally defined care pathways (red) and the personal life pathway (blue) of the patient. The payer/regulator is an invisible but omnipresent partner, shaping the PJ through funding and regulations

The person, the professional, and the system roles have inherently different views of the core care process, the information support they need, their desired outcomes, and their power to impact system design and goals.

The Person's Goal is to pursue health, which is understood as a resource for life. This sometimes entails becoming a patient but always involves me as a person. From the persons' perspective, the care process consists of an ensemble of consultations that cater to their health challenges as the patient journey (PJ) [25]. The PJ may move across many different organizations and professionals.

The Professional goal is to help patients attain professionally-defined health and functional goals by providing the knowledge and skills of their profession. The professional context is framed by the level (primary vs secondary care), by

profession (doctor, nurse, etc.), and by specialization (neurology, surgery, etc.). In addition, professionals are expected to follow explicit and implicit rules that exist in the care system that funds their activities.

The System/payer goal is to 1) maximize the care system value for the population it serves and 2) protect its members from economic ruin due to health care expenses. It serves its goal by hosting, organizing, and funding the front-line care process.

The paradox of care systems – Goal Conflicts

While the three roles all seek to improve health, there are potential goal conflicts among the three. The activities at the frontline result from more or less explicit negotiation between patient, professional, and system-level interests. Currently, the power balance in this negotiation lies in favour of the system and the professionals, not the patient.

The dominating business model of the early 20th-century health care systems was to "sell" biomedical knowledge and skills, not to patients directly but to the third-party payers [47]. In this context, it was the professional and the payers who, on behalf of patients, formulated patient needs. The strong power imbalance between the patients and professionals prevented patients from joining in the design of care systems. The patients were not invited, nor did they ask to be included, because when care systems were built, no one thought of patients beyond passive beneficiaries of professional care.

Thus, patients were effectively sidelined as legitimate stakeholders in designing and developing care at the frontline, middle, or top levels of care delivery systems. The current care systems still provide a care process designed according to this logic and rationale of system/ payers and professionals, not patients. Thus, value in health care systems has broadly come to be understood by professional-and system-defined outcomes.

To ensure that the three roles work well together, an explicit prioritization among these goals is needed. The three roles of the care system should be unified by a common overarching goal that can be used to align the sub-goals. The WHO claims that:

> *"Better health is, of course, the raison d'être of a health system, and unquestionably its primary or defining goal: if health systems did nothing to protect or improve health, there would be no reason for them."[47]*

Therefore, improved patient and population health is the unifying overarching goal of all three roles: patient, professional, and system/payer. Although the

World Health Organization (WHO) defines health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, the care system traditionally builds on a professional definition of health. As we have seen above, this leads to several issues where the professional tends to ignore the person.

The invisible implicit mental models of the current care system reflect a logic of siloed and episodic care for a single diagnosis to meet professionally defined outcomes. Current health care is designed to meet the goals of professionals and systems, not the goals of persons who carry the primary responsibility for their health.

Chapter 3 – What is PCC?

The person is the only legitimate decisionmaker on questions of the person's body and health. Designing a patient journey without an intimate knowledge of the person for whom we are designing it is like working in the dark. The person is the owner of the health problem. They must live with the treatment and are gate-keepers of all self-management resources. The person has insights and priorities relevant to the feasibility and effectiveness of both self-managed and profession-ally delivered care. Especially in a situation where multiple chronic conditions become the norm in ageing societies, life and health issues are woven tightly together, and the involvement and engagement of the person are paramount for success.

The professional role is to support the person in making an informed decision built on professional knowledge, experience, and skills. The patient cannot make deci-sions independently, as they may not have the necessary knowledge. The profes-sional cannot decide on their own, as they can not know how the decision might impact the person's life.

To ensure that the person is truly an equal partner in decision-making, the key is sharing power between patient and professional. In the messy world of frontline care, the issue of power-sharing is not so simple. Decisions are based on knowl-edge about what is possible, which options are available, and what likely conse-quences may be, both for the person, the professional, and others who may be affected. The person must have the necessary information, confidence, and sup-port to exercise power. The professional is an enabler of the person's decision by supporting the person in understanding their health challenge, understanding their options, and allowing them time and support for weighing their options against "that which matters" in their life [48].

What is PCC?

Every person is born with a body and health that they own and for which they are responsible. Health care's role is to support the person in improving and sustaining their health. Health care can provide means, support, and guidance, but the person is, by law and, in practice, the final decision-maker. Without understanding what the patient desires and finds attainable, the health care effort may be wasted or even cause suffering. Professionals and the system/ payers must, by design, sup-port and involve the patient in a co-creation of every decision on both goals and processes for care at all levels of care.

Only when patients cannot take an active role as custodians of their health does health care have a duty to take over decisions and provisions for improving and sustaining a person's health.

PCC embraces the patient as an equal partner in the design and co-production of the patient journey (PJ) towards meaningful goals for the patient, together with professionals and the system/payer. A successful PJ supports "what matters" to the patient within professional, legal, ethical, and economic constraints. All three roles need to be represented and included in the design, delivery, and evaluation of care.

PCC care is a sharing of power to ensure that the answer to: "What matters to you?" drives care decisions. Patients and professionals work together, within the constraints set by the care system, in a care process to achieve goals that are meaningful to the patient.

The PCC mental model

In a PCC care system, the overarching goal needs to include the patient perspective on health. We propose that to make PCC ubiquitous, it is necessary to build the patient perspective into every aspect of the health care system. The redesign of care from profession-centred to person-centred, from professionally-defined outcomes to "what matters to you?", and from diagnosis-specific pathways to patient journeys.

The PCC goal hierarchy

The PCC goal hierarchy from figure 4 aligns the goals from all three roles so that the tensions that arose from the lack of prioritizing PCC disappear.

- PCC builds on the tenet that the person has a legitimate right and duty to decide over their health and body. Health is understood as a resource for "what matters" to the person in their context and life.
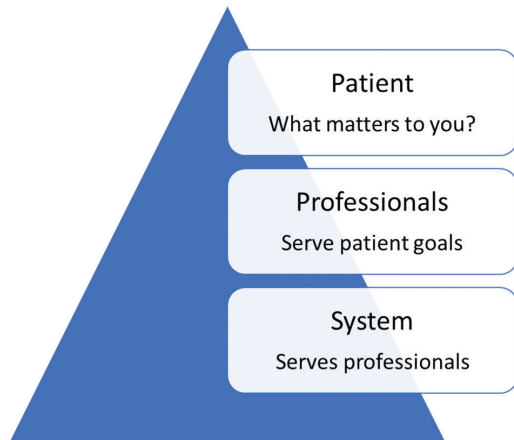

Figure 4: The new mental model: The overarching goal of the care system is to improve and maintain health, understood as a resource for "what matters" in the life of patients. Professionals serve "what matters". The system level, serves professionals.

- A Patient Journey (PJ) is the ensemble of care events organized by time across all diagnoses and providers, with the intent to improve or maintain health for the person.
- The frontline meetings that make up a PJ occur between a person and one or more professionals.
- Constraints set by the "system" shape the PJ meetings. The system ensures an organizational framework for PJ activities, funding for the PJ, and is responsible for the supporting structures and resources necessary to provide high-quality PJs.
- All other roles in the system support or contribute to one or more of the three roles: The patient, the professional, and the system. What is desirable and possible at the system and frontline levels is negotiated among these three.
- Quality of care is a PJ where goals are co-produced by all three roles in a negotiation where "what matters to the person" is the overarching goal. Patients and professionals translate "what matters" into realistic goals for care within the constraints of what is professionally, legally, ethically, and economically possible.
- Care decisions should be built on the best available evidence, understood as the judicial application of research, clinical and patient-based knowledge that serves to meet "what matters" to the patient.
- A PJ is successful when the patient, the only "traveller," arrives at the negotiated goals.

The following table outlines the role changes that will ensue from a PCC mental model:

Table 1: The role changes that will ensue from a PCC mental model

Old	Role	New
• Patients are passive recipients of care. • Health is professionally defined. • Care systems evaluate and treat health challenges that fit in professionally pre-defined diagnoses.	Patient role ⇒	• I am a person, responsible for my body and health and seek to be active in my self-care. • Health is a resource for "what matters" to me. • Care systems guide and support my quest for health on my terms.
• The patient is a visitor in the professional world. • The professional invites the patient to participate in evidence-based and professionally defined pathways and goals. • Professionally defined outcomes define treatment success.	Professional role ⇒	• The professional is a visitor in the patient's life. • The patient invites the professional to guide and support "what matters" using evidence and experience-based knowledge and skills. • The patient journey success is defined by "what matters."

Old	Role	New
• The system units are siloed by care level and profession. • The system funds, supports, and controls care delivery according to silo-based service production • System success is measured in cost-benefit, where the benefit is professionally-defined technical care quality.	System role ⇒	• The system units are self-organizing and responsible for patient journeys. • The system funds, supports, and controls patient journeys. • System success is measured in cost-benefit, where the benefit is a combination of patient-defined value and technical care quality

What does PCC look like at the frontline?

The hallmark of PCC is that the care goals, plans, and delivery support "what matters" to the patient. The primary goals of the PJ should derive from "What matters" to the patient. Professional goals are secondary because they serve the primary goals [49].

The PCC care process is a stepwise process consisting of the following phases [25]:

• To seek a sensitive and empathic process to understand "what matters" to the person. There are as many ways to listen to another as there are humans. Many texts expand on the theory, knowledge, and skills of frontline PCC and research-based frameworks designed to support effective person-centred communication that fits well with "understanding what matters."

• To translate "what matters" into goals relevant and realistic for care within safety, ethical, economic, and legal constraints. Patients cannot be expected to formulate a "what matters" that fits directly into goals relevant to care. Many things that matter to a person may not be possible for health care to influence. What matters may lie outside of that which is professionally, legally, ethically, or economically possible. "What matters" is only the first step in co-creating a care goal. The professional's job is to transform "what matters" into relevant goals for care that will support "what matters" within the realm of what professionals can do and what system/payers will fund.

• Shared decision-making is a defacto sharing of power. The professionals outline the options and enable the choice, but the patient is the final decision-maker. Being in charge fosters responsibility, ownership, adherence, preparedness, and trust. The patient's voice may be fragile and need support. The "what matters to you?" question is even more important for persons with less ability or self-efficacy to communicate. The system needs to provide training, time, and opportunity to build trust and inform patients sufficiently for them to be able to make their own decisions.

ISQua | International Society for Quality in Health Care

- The person may wish to involve people close to them or who are affected by their health and health decisions. Thus the shared decision-making process should explicitly address the involvement of other persons according to the wishes of the patient. In the case of people with limited ability to be responsible for their health, the parent/ guardian /caretaker must be acknowledged and actively included in decision making.
- To plan and deliver the patient journey in alignment with "what matters" and best practices as recommended by the professionals, in collaboration with the patient.
- To evaluate care in terms of "what matters" as the overarching aim. Sub-goals should include the patient experience, patient and professionally defined health and functions, system/payer defined cost-benefit, where benefit includes both patient and professional perspectives. All three roles must participate in the evaluation.

What matters to you – WMTY?

"What matters to you?" («WMTY?»), first coined by Barry in his seminal paper [7], has come to inspire a new and very concrete understanding of PCC. The «WMTY?» question is not a method but rather a concept that encourages providers to refocus their attention from diagnoses and medical problems to identify those issues that truly matter to the person [13]. The Institute for Healthcare Improvement (IHI) has championed what they call "a flipping of health care," where «WMTY?» drives care decisions:

> "The essence of flipping healthcare, as argued by Michael Barry and Susan Edgman-Levitan, is that providers should ask, "What matters to you?" as well as, "What's the matter?" (…) Flipping healthcare means flipping the balance of care from the hospital to the community; the balance of delivery from individual providers to care teams; the balance of power from the provider to the patient and family; the balance of costs from treatment to prevention and co-production; and the balance of emphasis from volume to value and from healthcare to health." [50]

«WMTY?» is a question that most people have not given much thought to, so it may take time to develop an answer. What matters may also change swiftly during illness, as insights and priorities change. «WMTY?» may need to be revisited regularly or when needed.

This question leads the professional to be curious and explorative about the other. It enables the professional helper, with all their bio-psycho-social knowledge and

skills, to understand better how to fit that help into the life of the other. It is a pragmatic way of operationalizing Kirkegaard's proposition:

> *"If One Is Truly to Succeed in Leading a Person to a Specific Place, One Must First and Foremost Take Care to Find Him Where He is and Begin There. This is the secret in the entire art of helping.*
>
> *Anyone who cannot do this is himself under a delusion if he thinks he is able to help someone else. In order truly to help someone else, I must understand more than he–but certainly, first and foremost, understand what he understands.*
>
> *If I do not do that, then my greater understanding does not help him at all. If I nevertheless want to assert my greater understanding, then it is because I am vain or proud, then basically instead of benefiting him I really want to be admired by him." [51]*

For the «WMTY?» question to support PCC, professionals must acknowledge their role as "system agents." Therefore, the answer to "WMTY?" needs to be shared sensitively with other colleagues who work with the same patient. In a complex PJ with many professional contributors, it may be important to restrict the dialogue about «WMTY?» to a few designated care professionals who can support continuity and trust. Sharing sensitive issues indiscriminately may threaten trust. However, being asked the same questions repeatedly can also endanger trust. Therefore, discussing the formulation and sharing of the answer to "WMTY?" with the patient is critical. Documentation of «WMTY?» is a particular concern since, without such documentation, new health care professionals' ability to maintain consistency at the system level is difficult.

The case for benevolent paternalism

Professionals must make the best choice they can on behalf of the patient in some extraordinary situations:

- When you cannot know the patient's wishes (unconscious patient).
- When the disease or condition impairs the patient's ability to make decisions.
- When the patient is too overwhelmed **and** there is no time to work with them.

Making choices on someone else's behalf is the exception, not the norm. The professional dual duty in such situations is to 1) act in the presumed best interest of the patient and 2) to help restore the patient, as far and as soon as possible, to a state where they may again collaborate with the professional in voicing "what matters" to them [48]. As soon as the extraordinary situation has passed – if possible and relevant – revisit the decision with the patient to learn and adjust care to the patient's preferences.

Chapter 4 – What are the implications of PCC

PCC leads to anticipatory/proactive care

It is not possible to <u>not</u> manage your health. We all manage our health, in good or bad ways. A basic tenet of PCC is to support the person who "owns" a body to self-manage the health of that body in the best possible way.

Self-management can theoretically be divided into what the person does to seek treatment for current symptoms, diagnoses, and conditions, and to avoid future health issues (e.g. quit smoking, or treat hypertension). Health care is currently designed to provide reactive care for already diagnosed conditions. However, re-active care does not do the best job of supporting the person in maintaining their health. The re-active health paradigm stems from a view of the patient as a passive recipient of professional care. With PCC, the patient role changes into an equal active, informed partner. A partner who has a strong interest in reactively treating and proactively stopping a condition from developing further.

Pro-active care includes self-management activities, primary and secondary pre-vention, early intervention, and anticipatory management of current conditions. It often produces better results in terms of health for the individual and is less costly both for the individual and the payer [53]. Proactive care is usually heavily depen-dent on the person's involvement in managing their health. It makes sense that the self-care resources of the person are most efficiently marshalled when the goals of self-care align with other life goals. With truly shared decision making, the PCC approach is also the approach that will support patient motivation for healthy life choices. We know that solid patient involvement and engagement outcomes improve [52].

However, competing life priorities and goals may override rational, proactive health choices. Pro-active self-management is often hard work on the part of the patient with intangible "non-event" rewards, such as not getting a heart attack. Key to the success of pro-active care is strong ownership of the goals of pro-active care. Showing how life and health goals are tied together may foster ownership and en-gagement in self-care, improving outcomes. By focusing pro-active care explicitly on risks that might threaten "what matters" to the patient, care activities become meaningful. We propose that pro-active care is a consequence of PCC.

The link between PCC and pro-active care is perhaps the most important implica-tion of PCC – It prevents undesired health events for patients. For professionals,

it produces better outcomes. For the system/ payer, avoidable care is an attractive outcome. It theoretically results in care for the population that is better, and often [54], but not always[55], cheaper than crisis management.

Proactive care is fundamentally different from reactive care. All proactive and preventive care builds on the early identification of risk as a basis for early intervention. Proactive care has implications for the organization of care and design of PJs.

- Recognizing the person themself as <u>an active partner and resource</u>; they are always there, have the best opportunity to identify risk, and have the most to gain from avoiding a potential crisis.
- Systematic identification of risk before the risk manifests as the undesired outcome. The risk analysis could be done by reviewing possible risk situations or directly monitoring risk factors.
- Risk identification is only effective if coupled with a threshold for action and an action plan.
- The person is almost always an essential partner in the risk-mitigation activity. They must have access to the knowledge, skills, and training to do what is agreed. This requires support for self-efficacy and health literacy [56].

Pro-active care is not in itself PCC. PCC is defined by equality and power-sharing in the co-production of pro-active care. In opening up for genuine power-sharing, the patient is supported in making their own choices on their terms. Adherence and compliance to one's own decision are much more likely than if it is thrust upon one [57].

When the patient makes poor choices…

Beware of introducing self-care goals that are top-down societal or professional goals. Health care professionals will experience patients who do not follow their advice. For example, the smoker who cannot quit, or the young diabetic who consistently has a high long-term blood-sugar level [58]. This can be professionally frustrating. However, the health professional is **not** present to make patients choose the «right» action in terms of health. Patients have the right to put their health second to other life goals. We know that finger raising, shaming, and blaming patients for unhealthy life choices and non-adherence do not produce the changes we seek. Instead, it induces hostility and loss of trust [38].

Such challenges can be reviewed and discussed in an open, transparent, non-judgmental, and respectful discourse. Sometimes this will result in a new understanding and a better decision for both parties. There are tools such as "guided self-determination" [59] and "motivational interviewing" [60] that are developed to unveil, both to the patient and the professional, the basis for the inability,

unwillingness, or even disagreement on following through on professional advice may be: As Zoffman writes:

> *"…Shared Decision Making in chronic care may be a question of professionals gaining insight into patients' decisions, rather than the opposite"* [61].

When the patient disagrees with professional advice

Some health professionals fear that PCC may make professionals responsible for treatment they feel is wrong. This fear is unfounded. Neither professionals nor patients can force decisions upon one another. Patients can not force professionals to provide illegal, harmful, or unprofessional care. Both the patient and the professional are entitled to disagree with one another. The care choices that are made can be vetoed by either patient or professional. To move forward, both need to find solutions acceptable to both parties.

In the few cases where the patient wishes for something illegal or outside of economic or ethical constraints, the professional must make this clear to the patient in an empathic and non-judgemental dialogue. At this point, it is fair to issue a warning to patients: If a patient wishes to act in a way that is against the professional's explicit recommendation, it follows that the patient must also take responsibility for that decision. There may be good reasons for such a decision, such as not pursuing life-prolonging treatment for a terminal illness.

The professional's responsibility is to make the patient aware of the possible consequences. Different countries will have different rules on how to document such disagreements. Both parties should make sure that the professional advice, the patient decision, and the arguments from both parties are documented in the health record.

PCC leads to integrated care

In a profession-centric system, professionals tend to work towards professionally defined goals that may not align with one another [49]. In a redesigned PCC system, all professionals should work towards "what matters" as defined by the patient. The overarching patient defined goals have the effect that professional goals must align with the overarching common patient-defined goal. The patient defined goal has a coordinating effect. The professional goals do not disappear, but they will be weighed and prioritized in the order of importance for the overarching patient-defined goal.

This alignment process is especially important in multimorbid PJs, where professionals and patients must carefully weigh and consider the possible pros, cons,

and interactions likely to result from the combination of multiple single-disease recommendations [62]. The multiple lines of advice should ideally result in a well-orchestrated concert for the maximum overall benefit for the patient. There is no generally accepted method of weaving condition-specific treatment into a coherent, integrated care plan [63, 64]. However, competent professionals can suggest a gradual starting plan of prioritized activities, then stepwise test and adjust it. Multi-morbidity care plan building is a team effort, as one person rarely has all the answers regarding what is both possible and realistic in areas where they are not experts. Complex coordination work can be time-consuming and specialized work that requires the timely involvement of each specialist to deliver their piece to the larger puzzle.[65] Integrated, coherent, comprehensive, or team-based care results from a PCC approach.

Importantly, we wish to underline that integrated care is not in itself PCC. The distinction between the two is essential because we frequently see a misunderstanding that if care is integrated to accommodate a person's multiple problems, it is also claimed to be person-centred. PCC is defined by equality and power-sharing in the co-production of care planning and delivery. Integrated care is simply the coordination of care resources across time and place. If such coordination is undertaken without aligning with the patient's "what matters," care can be integrated but not person-centred.

PCC leads to improved outcomes

Although the basic foundation for PCC is that it is "the right thing to do," the logic of health care professionalism demands that all changes to care decision-making be grounded in a demonstration of improved outcomes. We face hard questions like: Could PCC lead to poorer outcomes? Are we risking hard-earned progress grounded in standardized and biomedical approaches if we lean too far into PCC? In other words, is there a conflict between PCC and successful biomedical standardized care? Do we have to choose one over the other?

Fortunately, no research we are aware of supports this fear of contradiction between the two ways of thinking. On the contrary, the research on the effects of PCC generally supports the claim that PCC and biomedical care are complementary. Biomedical expertise is the basis for the person to seek support and help from health care in the first place. The same expertise is necessary, also when care serves personal goals. The research that has been done in this still-young area is supportive of the claim that PCC and technical care are complementary and probably even synergistic.

While a full review of the documentation for PCC here is outside the scope of this book, we will present some of the most compelling work that has been done to show that PCC improves outcomes:

Weiner showed that physicians listening to and considering their patients' concerns when making clinical decisions led to improved biomedical outcomes. Weiner writes:

"We found that when physicians take into account the needs and circumstances (that is, context) of their patients when planning their care, individualized health care outcomes improve. Although it may seem intuitive that addressing a patient's inability to pay for medication results in improved diabetes control, addressing a misunderstanding about instructions essential to self-care results in lower blood pressure, or addressing competing responsibilities for the care of a chronically ill family member results in fewer urgent care visits, this study may be the first to document an association between contextualizing patient care and patient care outcomes." [66]

In a rigorous Cochrane review of 19 studies involving a total of 10,856 participants, Coulter found the same effect of personalized care planning:

"We combined and summarised results from studies that measured similar outcomes and found that involvement in personalized care planning probably led to small improvements in some indicators of physical health (better blood glucose levels, lower blood pressure measurements among people with diabetes, and control of asthma). It also probably reduced symptoms of depression, and improved people's confidence and skills to manage their health"[32].

However, in a review conducted by the WHO, where they combined the concepts of PCC and integrated care, they were surprised to find that the combination of the two still lacks documentation. [67]. We posit that the main biological effects of PCC arise when PCC also leads to improvement in other quality areas, such as integrated and proactive care. In a scoping review of digitally supported Person-centred, integrated and proactive care, Berntsen found that:

"…, each component is often studied on its own, so that the maturity of each element in comparison with other interventions in the same vein and the synergies between them have not been subject to academic study. [68]

The research in this area is dominated by a reductionist approach that does not acknowledge the complex adaptive system mechanisms shaping care processes and outcomes. By trying to isolate the effect of PCC alone, researchers are effectively ignoring how PCC impacts other quality of care mechanisms. Conclusion: synergies among PCC, integrated care, and proactive care are essential to achieving hard outcomes. In plain language, listening to patients is ineffective if what you learn is not shared with the relevant professionals (integrated care) and acted upon

to promote effective care for current symptomatic conditions and future threats arising from the current situation (pro-active care). It is not rocket science, but it is complex in that research needs to pay attention to the synergies of PCC, integrated and pro-active components of care to expect improved outcomes. There is an urgent need to close this knowledge gap.

Chapter 5 – How do we make PCC the norm?

"We can't control systems or figure them out. But we can dance with them!" [44]

Our analysis above showed that care system owners and payers know that it is vital to respect the population's wishes through their representatives because these are either the de facto owners of public care systems or the customers who indirectly or directly pay for the business as customers. Care systems already have built-in high-level goals of PCC. Although we don't have to argue for PCC, incorporating PCC into the vision and mission statements is not enough.

Identifying action points for change requires understanding health care systems as a "Complex adaptive system" (CAS) and applying systems thinking to the challenge. Complexity theory can, at least in part, help to explain why the introduction of PCC is so challenging. A "quick guide" of the central concepts can be found below. In the iceberg model (see Figure 2 earlier), the next step is to analyze how system structures support the processes that arise from the system. If these structures are not aligned and clear in the prioritization of PCC, any competition for resources in terms of time, attention, personnel, or money will favour non-PCC. The main structures in care systems are their regulations, organizations, incentives, information, research, and education structures.

Complexity theory – a quick guide:

A complex adaptive system (CAS) is not directly predictable or governable. It consists of multiple self-organizing units controlled by local inputs and outputs, incentives and logic, which may change over time. The units are interconnected and interdependent. A shift in one place in the system may have ripple effects somewhere far away from its origin, leading to unexpected outcomes.

Intentional modification in CAS is unpredictable and messy, but it is possible. History shows that we do it all the time as societies diverge and evolve in terms of values, principles, and logic. It may be hard to articulate the logics that governs a network, a system, or a society, especially if the fundamentals are taken for granted so that we no longer question or put words to it.
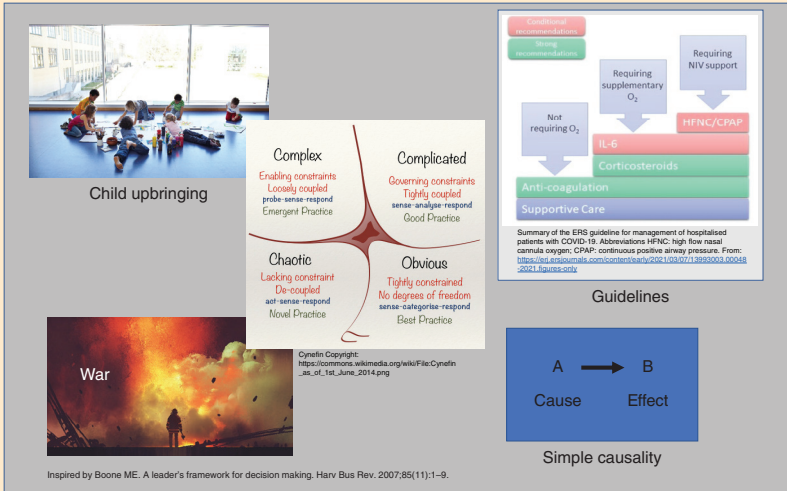
Figure 5: The four areas of complexity theory adapted from: [69]

Briefly, complexity theory sets out four areas of increasing complexity in terms of the cause-effect relationship (see Figure 5) [69–71]:

- **Simple events:** events with a known linear relationship between cause and effect. Example: Treatment for cardiac arrest is Cardio-Pulmonary Resuscitation.
- **Complicated event:** The nature between cause and effect is known but dependent on other factors that can be illustrated with a "flow-chart." Experts train to detect the decision points and their dependencies Eg. chemotherapy X for cancer Y, will not work if the patient suffers from kidney failure.
- **Complex events:** the cause-and-effect relationship are multiple and un-clear, although several areas linked to the outcome may be known. There may be multiple cause-event steps within a cause-event chain involving multiple interconnected self-organizing independent units that respond to inputs according to local logic. Change management starts by using available theory and experience to hypothesize how the system works, formulate ideas on how to change the system, and then trial the potential solution(s) iteratively and observe effects. Judgment about what works and why will be based on a reflective evaluation of the theory and ob-servations. Example: We know that all parents seek food, shelter, safe environments, schooling, playmates, etc., for all children, but in different measures and patterns for each child. Parents will iteratively observe, respond and adjust to the challenges that occur for each child.

- **Chaotic events:** The cause-and-effect relationships are unknown and unknowable. Managing a chaotic situation is all about stabilizing bits of the system so that these sub-parts can be brought back into the realm of complex and complicated. Example: War, where the contributing agents are de-stabilizing and unpredictable, with resulting catastrophic instability.

All four types of cause-effect relationships exist in healthcare, but simple and complicated approaches are the most common in clinical work. However, complex approaches are probably more apt in many situations. Chaotic situations typically occur in catastrophes, where all of society may need to step up to manage the situation.

Systems thinking – a systematic approach to change in CAS

Closely linked to CAS is systems thinking, which

> *"…is a set of synergistic analytic skills used to improve the capability of identifying and understanding systems, predicting their behaviors, and devising modifications to them in order to produce desired effects. " [1]*

Systems thinking provides us with the following general leverage points: "Places to Intervene in a system (in ranked order of effectiveness)

1) Transcending paradigms
2) Paradigms: The mindset of which the system, its goals, structure, rules, delays, and parameters arise.
3) Goals: The purpose of the system
4) Self-organization: The power to add, change or evolve system structure
5) Rules: Incentives, punishments, constraints
6) Information flows: The structure of who has and does not have access to information
7) Reinforcing Feedback loops: The strength of the gain of driving loops
8) Balancing feedback loops: The strength of feedback relative to the impacts they are trying to correct
9) Delays: The lengths of time relative to system changes
10) Stock-and Flow structures: Physical systems and their nodes of intersection
11) Buffers: Sizes of stabilizing stocks relative to their flows
12) Numbers: Constants and parameters such as subsidies, taxes, and standards. "[44]

Using these tools to analyse health care, first comes leverage points 1–3, which all focus on the explicit verbalization of the paradigms that underpin health care's "raison d'etre." What is the overarching goal of the system? Mental models are often so deeply embedded in our minds that we do not question or even verbalize them because they seem self-evident. Previously, we described the new PCC mental model (see Chapter 3), as changing from a health care service for professionally defined goals, to one that serves the patient's goals.

To apply a PCC mental model, it must guide the design of the other structures of the care system, including their "…interconnections, the understanding of dynamic behaviour, systems structure as a cause of that behaviour, and the idea of seeing systems as wholes rather than parts"[1]. Five core structures make up every national health care system:

1. The organizations that make up the health care system, including the different agents that share health care labour across complementary roles and tasks. They consist of humans, professions, organizations, and levels of care.
2. The laws and regulations define the organizational units, roles, and boundaries.
3. The information systems that support information flow among the agents. This includes both analogue and digital information flow.
4. The funding and incentive systems that motivate or restrain behaviour include monetary incentives, quality indicators, and other less transparent factors, such as cultures and traditions.
5. The educational and research systems that produce knowledge, educate, and train professionals in the theory and skills of the health and care professions.

These five structures each consist of agents that are, to some extent, self-governing agents. All humans in the system, from the top-level managers of a hospital to the assistant nurse, have some level of self-agency. They can choose how to carry out a task or an expectation within the constraints set by the system structures. Changing the mental model to PCC, educating, incentivizing, facilitating, and trusting them to do the right thing, makes change happen. When they meet conflicts, resource scarcity, and barriers, listening to these agents is perhaps the most important feedback loop. Listening to the patients and their experience of how the system works is another feedback loop in the service of patient defined goals.

Going through all the system structures with PCC in mind is the next step. If we are also interested in hard outcomes, it is essential to consider the associated implications of PCC: integrated and pro-active care. It is a PCC, integrated and proactive care process that improves outcomes.

Table 2 below identifies Key areas for consideration in the PCC care system. This table is not meant to be exhaustive, nor is it final. It gives an example of how it is possible to break down the overarching goal of PCC into separate areas of focus, which each require activities for change.

Table 2: Key areas for consideration in the PCC care system

Goal	Care Delivery Organizations	Legislation and regulations	Incentives and funding systems	Information systems	Education and research
PCC	Build and embed PCC into the culture, including the patient journey as a mental model of the care delivery

Review the patient journey, focusing on the "WMTY?" question, the handovers, and the self-management and care delivery through the lens of the patient experience.

Educate and support shared decision-making and co-production with patients. | Review expectations of patient value evaluation at individual and group levels.

Make care safety a system responsibility based on learning from adverse events.

Patients are by default in charge of their health care data and decide with whom to share across organizations. Exceptions are made to accommodate emergencies and situations where patients cannot take on this responsibility. | Patient value evaluation, both qualitative and quantitative, are linked to incentives.

Link incentives to patient goals and patient experience in the patient journey. | Recording patient goals are mandatory in health documentation

Build patient journey documentation across professions and organizations

Ensure transparency and information sharing across the patient journey.

Collect patient feedback on "what matters." | Teach PCC and health care systems knowledge

Identify valid and reliable ways to measure PCC and depersonalization.

Special focus on building knowledge about the experiences and needs of marginalized and vulnerable populations.

Make innovation projects together with Care and Information systems. |

Goal	Care Delivery Organizations	Legislation and regulations	Incentives and funding systems	Information systems	Education and research
	Establish measurements and observations of both achievements of PCC and the threats to PCC, such as depersonalization, emotional burnout, and transactional care. Review the patient experience of marginalized and vulnerable populations. Work with Research and education to innovate care delivery towards PCC.				
PCC ⇒ Integrated care	Build awareness on patient journey quality for persons with complex and long-term needs. Educate and support teamwork.	According to patient wishes, ensure the free flow of information to all relevant parties.	Bundling of payment for complex patient groups across organizations, where the organizations share incentives and penalties according to patient journey outcomes.	ICT-Tools for teamwork: Proactively identify high-need and high-cost patient groups	Educate all health professionals about the division of labour and roles in complex patient journeys.

Goal	Care Delivery Organizations	Legislation and regulations	Incentives and funding systems	Information systems	Education and research
	Establish a culture for shared plans and support for the following link in the care chain.	Allow pro-active identification of patients with complex and long-term care needs.	Explicit funding for "shared practices" – i.e. coordination activities that take time and expertise.	Collect patient feedback on the discontinuity of care	Innovate and analyze the effects of teamwork and shared work practices.
PCC ⇒ Proactive care	Systematic self-management support in areas of health literacy, self-efficacy, and skills training. Establish low-threshold professional support in case of emergency for high-risk patient groups.	Allow proactive identification of threats to "what matters" and active management of those threats through monitoring risk factors, alarms, and action plans. Especially important for vulnerable and marginalized populations.	Bundling of payments, especially for high-cost, high need patients.	Provide digital self-management support wherever possible. Include sensors and self-reported experience, risk, and outcomes data in documentation. Provide automatic alarms of increasing risk, coupled with decision support.	Education: Build individual-level risk-management into professional practices Improve identification of high-cost, high need groups with effective broad interventions. Research how to recognize patients who will benefit from specified proactive care programs.

In complex systems, common to all change management is a goal-setting activity, followed by a plan–do–study–adjust cycle adapted to the local situation, in line with Deming's quality improvement theory. In the planning phase, we would encourage special attention to:

- Identification and naming of important structures and interconnections and examining gaps between the current way of operating and a PCC vision. What are the gaps, and how do they matter? This is a critical phase where the agents who need to change would be invited to identify overarching system goals and the smaller pragmatic goals that are within reach.
- The information flow (regulatory signals) that allow self-organizing units to adapt their activity to their local purpose and overarching system goals are core to change management. Information flow should have a supporting and enabling role, not a controlling function.
- Building self-organizing capacity means that the units that enact and support PCC should be trusted, educated, supported, and encouraged to invent their approach toward the overarching common goals. Building capacity for local action requires an explicit dismantling of shaming and blaming cultures and a building of committed cultures that can risk a trial-and-error approach. Without errors – no learning occurs. Fail fast and small and use it to learn and adjust the approach.
- Create feedback loops that reflect the mental model that documents and guides the self-organizing units. Failures or setbacks are learning opportunities. Feedback loops are tools that can be linked to incentives and disincentives to guide the system in the desired direction.

We stress the importance of seeking out patient journey experiences at every turn. Creating many ways of listening to patients and their experiences to understand how their journey helped them manage and improve their health to support their "What matters" in their lives. Listening to the patient's voice can be quantitatively reaching out to many patients and qualitative explorations of specific patient journeys. Invite patient and caregiver collaborators onto improvement teams to contribute their broader system insights from firsthand experiences and observations. Spending time reflecting upon and learning from concrete patient experiences is a meaningful and effective motivator for change across the care system. Do not forget to think in journeys that span the system instead of silo experiences. It is the chain of care that produces the final result.

Beware that there are systems within the systems and that system borders are inherently indistinct. Also, regulatory signals are not only "official" because they are explicit and transparent in the public domain. "Invisible" regulatory signals reside in culture and traditions, family values, or personal history and may influence how a person or an organization might choose to act.

The PCC – language and information flow

Building a PCC information flow requires attention to our concepts and language for PCC. The words are not new, per se, but are currently not part of documentation and regulation signals in the system. The following three concepts will be central to feedback loops (see also Fig 6):

- **The person** – the identity and the person's narrative, explains and supports "what matters" and why. Putting words to identity prevents professionals from making the error of ignoring the person in the patient. Making it more personal introduces a level of humanity into the interactions that protects us from treating each other as "mechanics."
- **The "what matters"** to the person and its translation into "relevant goals": This drives decisions in the patient journey and is the basis for evaluation of the journey. Careful documentation of "What matters" directs prioritization and tailoring of the PJ.
- **The patient journey** is the plan and the actual delivery of care that should ideally embed "what matters" as an outcome and reflect strong self-management as the core of the care process. The patient and professional co-create the plan and its delivery so that journey is meaningful, feasible, effective in reaching its goal, and as comfortable for the person as possible. The PJ documentation may include a patient journey narrative as part of the history and the patient experience feedback. The care plan, seen from the patient perspective, should outline who does what when for all the patient's conditions and should also document what has already been delivered and what is upcoming. Suppose a critical element was not executed as planned. In that case, this fact should also be documented, together with a review of why it did not happen and how to re-establish continuity with the PJ.

The **person:** Who are you?
- What is your health challenge?
- How does the health challenge impact you?

The **goal**:
- What matters to you?
- What technical goals will serve «what matters»?
- What is realistic within the system constraints?

The **patient journey**: How do we get to the goal?
- Patient: What are the personal values, needs and preferences?
- Professional: What are the technical pathway choices?
- Professional and patient: Who does what when?
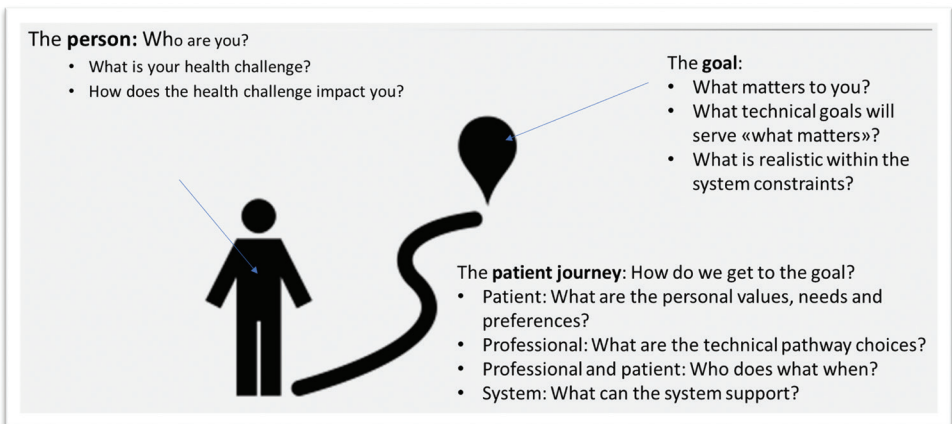- System: What can the system support?

Figure 6: The Person, the Journey, the Goal

The feedback loops

The revised system's logic should support professionals in creating person-centred, integrated, and proactive care.

The feedback loops do not have to be linked to formal incentives to work. Providing timely and specific information may be enough to support change. At this time, we have little experience on how directive the feedback loop process should be, as there is empirical evidence of both effects and side effects following the introduction of technical quality indicators [72], PROMs, and PREMs in funding algorithms [73]. It is also important to remove disincentives to PCC, i.e. regulations that impose cost penalties on delivery of PCC.

Measurement and observation are not done for their own sake but as a **guide to change** management. Without measurement or observations, those responsible for processes are "blind" to their progress. If evaluation and observation are to make a difference, they must identify the relevant care situation and provide meaningful feedback to those responsible. Also, if measurement is to be taken seriously by the evaluator, e.g. a patient, the act of evaluation must be intuitive, non-ambiguous, not overwhelming, and it must make sense to everyone. The transparent use of the measurements should not harm or penalize the evaluator. This will immediately be a reason for "gaming," i.e., changing the evaluation to minimize harm to oneself.

The **chain-of-care** that makes up a patient journey poses a challenge in observation and measurement for feedback. Although it does make sense to evaluate each link in the chain of care separately, the final result for the patient is also highly dependent on how all links work synergistically together. At the same time, feedback should provide insights relevant to the specific organizational or professional agents that contributed. Thus, feedback from patients on their patient journey experience requires both a look at snapshots along the way and the journey in its entirety. Finally, it is interesting to learn if the journey met its original goal. Several instruments are relevant for snapshot-evaluation of shared decision making in the consultation [74] and the patient's experience of the consultation [75–77], but not so many that review the patient experience of the chain of care or patient journey [25]. We believe that the patient narrative might be an important way to review the entire journey, especially in complex cases [78].

Continuous goal assessment: Evaluation of goal attainment is important to learn and adjust the journey along the way. The evaluation is either done by the patient alone or by the patient and professionals together [79–82]. There are some strict formal ways of doing such evaluations, where the expected functional outcomes and timing for the evaluation are defined ahead of time [83][84]. Other evaluations

simply record the patient-defined health issues at baseline and then evaluate progress on these measures at follow-up [85–87][82, 88]. The goals and their attainment can be recorded both in a narrative and a quantitative way. The quantitative evaluation is easy to aggregate up to group levels. The narrative review is performed by the patient and professional and informs the continuous adjustment of the care process. The aggregate values are anonymized and inform decision-makers [89].

Transparency and trust

The joint patient-professional review of the PJ, of both PCC and technical quality, turns the evaluation into actionable learning points. The more concrete, the more open and the closer in time, the more valuable and enlightening the evaluation will be.

Please note that the feedback loop needs transparency and openness to succeed. Only when the patient experience is honestly reported and coupled with an open and non-judgemental professional reflection will the evaluation generate direction for improvement at both individual and system levels. To facilitate such honesty, it is imperative that neither patient nor professional fear the review. Patients have reported that they feel vulnerable and are afraid of being punished by their providers should they express openly critical comments [90]. Likewise, professionals have reason to be wary of evaluations that could uncover errors and failures that might exact penalties [91]. To support safety and learning, any critical feedback from any source should be applauded as a valuable source of learning.

Creating the safe generous, trusting, and open atmosphere needed to make feedback a constructive exercise is vital. It is necessary to construct a review process that builds on, strengthens, and protects trust to enable true learning. The process should effectively shield both parties from any potential negative consequences.

Here are some examples of doing this:

Group-level aggregation of patient feedback and experiences, where patient and professional identities remain anonymous. Such feedback works best if they reflect directly back on a known entity and time.

Individual review: Review an individual patient journey, as recorded in the health record and patient-reported material, by a professional or board of professionals who were not involved in the patient journey and know neither patient nor professionals.

Patient stories: Collections of patient narratives of their PJs or sections of their journeys. The patient may or may not be anonymous. The patient interviews should

be conducted by someone not part of the provider team, such as a researcher or a patient-partner. The organization shares the story to foster reflection dialogue and inspire improvement [92, 93].

Continuous formative dialogue: The professionals encourage patients to provide direct feedback for improvement but do not aggregate or report the feedback to the system. Some professionals use formal validated tools for feedback [94][95]. Others simply establish the feedback loop as part of each consultation. This approach is useful when there is continuity across providers but may be less valuable in a setting with many professionals working independently.

Digital tools for PCC

The role of creating supportive information systems for the transformation toward PCC can not be underscored too strongly. Information tools that document and display the person, the "WMTY?" and the PJ care plan and delivery are key tools for both patients and professionals to succeed. The information necessary to construct the patient journey includes sharing goals plans, designing workflow, and using health data analysis for risk management. Evaluation at the individual and group level guides managers and allows linkage of incentives to positive achievements. Although simple PJs can be supported by analogue information flow, this will not suffice for a growing group of multi-morbid patients with complex and long-term needs. Digital support designed to support PCC systems will play a central role in reaching strategic targets for our care systems. The WHO has declared that digital health is essential for reaching their policy goals [96]. The WHO underlines that digital health may support universal coverage, especially through cost-containment and wider geographic access to health care information and decision support.

While digitalization lowers the threshold and improves accessibility to care for broad population groups, it may also increase barriers and hamper access for others. The older citizen who is not a digital "native," the cognitively impaired, and the person without financial resources to obtain digital tools and internet access are all at risk. Using analytic tools to spot inequities that arise from digitalization and addressing these are necessary [97]. There will always be a need to maintain face-to-face and analogue services at the population level to ensure access and quality for those who can not use digital support tools.

Ideally, the patient journey documentation should be accessible and even owned by the patient, not just as a "rhetoric." The patient should be supported with digital tools to see, monitor, add to and decide who to share their data with. Exceptions for non-consensual access to data for legitimate reasons, such as emergencies or

cognitive impairment, can co-exist with strong patient ownership of data. Zanaboni found that patients who accessed their digital information have found:

> "Clinical advantages to the patients included enhanced knowledge of their health condition (565/691, 81.8%), easier control over their health status (685/740, 92.6%), better self-care (571/653, 87.4%), greater empowerment (493/674, 73.1%), easier communication with health care providers (493/618, 79.8%), and increased security (655/730, 89.7%). Patients with complex, long-term or chronic conditions seemed to benefit the most."[98]

On paper or in digital format, information systems that provide tools to document and review the patient journey are key to moving from fragmented profession-centred reactive and episodic care to person-centred, integrated, and pro-active PJs. Making the PJ tangible allows us to answer questions such as: What do PJs look like? How can we link funding to PJs? How can we evaluate PJs in terms of both technical and PCC quality?

Today's electronic health care records and digital health care tools reflect the fragmented professional organizations they were developed for. The organizational demands for documentation and administration of patient data dominate EHR functionality.

The next generation of digital tools should be designed for the new mental model:

"What matters to you?" People do not necessarily have a ready answer to the question, "What matters to you?". Digital tools can support persons in developing and sharing their narrative and sense of identity and life projects. Persons can find tools to create an overview of the critical areas for their health and well-being, providing an account of their strengths, needs, values, and preferences, and sharing that effectively with the care professionals that work with them. Digital Shared Decision-Making tools educate and support the co-production of critical decisions in disease-specific care pathways. Health information sites are invaluable to citizen health literacy and empower the patient to understand their condition, how it is treated, and the prognosis. Digital access to their electronic health record helps patients understand their care and revisit the chosen decisions and strategies. Digital feedback from patients regarding how well professionals involved them in their care, including relevant PREMs and PROMs, is also part of the digital toolbox for PCC.

Integrated care: The PCC plan is also an integrated care plan. However, the continuous update of the shared care plan is challenging to maintain with analogue tools alone. Diagnosis-specific and evidence-based care plans are the basis for any care plan and will often be sufficient for single disease pathways. However, when

there is more than one diagnosis, the digital tools should support merging diagnosis plans into personal plans. It is essential that the resulting digital care plan be shared with all contributors, including agents outside of the health service such as the patient, the significant others, social services, and schools.

A shared care plan serves many functions as it provides all parties with an overview of goals, roles, and tasks. It shows what is planned and what has already been delivered. It provides an update on evaluations made by the patient. It is an arena for synchronous and asynchronous team communication, which helps the team stay updated and react to changes or unexpected developments. Workflow optimization tools may help organizations translate patient-care plans into employee workflow. Care process monitoring could secure the care system's compliance with the care plan and alert the relevant professional if critical services were not delivered, as planned.

Proactive care: In PCC, the patient stays informed and is as active as they desire to be. Risk management is systematic and planned. The digital tools for supporting self-management range from providing information to guidance for self-care. Examples include diet and exercise apps and diagnosis-specific apps, such as diabetic blood sugar control apps. In risk management, wearable sensors can help monitor risk factors to support early interventions, such as weight increase in heart failure patients or infection risk in COPD patients.

It is outside the scope of this text to review rapidly emerging opportunities for the digital support of PCC care, but note that digitalization is a central tool that, when adopted with care, can support the goal of PCC.

Chapter 6 – Concluding remarks on PCC

PCC is an intentional system design feature. Above, we have outlined the general principles of the PCC system, mainly for the frontline. The system transformation needed to make change happen must be translated into concrete actions. We do not claim that this is an exhaustive overview of all areas that need attention. Still, we hope our content might inspire other authors to take up the challenge to improve and expand on this outline of facets of care systems and practices that need examination when re-designing care for PCC.

It is beyond the scope of this text to offer further detail on how to generate the system-level changes needed to achieve PCC. The general principles that lead to success will still need to be tailored to local contexts, considering local culture, traditions, history, resources, and current practices.

The current profession-centric care system was built with the best of intentions. To reform our care systems, we must build on its strengths, keep the professionalism, but redirect its goal. It will not be easy. It will be hard work, and it will take time. We believe it is worth it. The rewards are improvements in all the quadruple aims: Improved patient experience, improved health and function, improved cost-benefit, and improved professional experience.

Care professionals are "visitors" in the patient's life. The patient is the host, guide, and enabler of the healing journey. The care system's goal is to enable the person to thrive in their life with as little support from health care as possible.

References

1. Monat, J.P. and T.F. Gannon, *What is systems thinking? A review of selected literature plus recommendations.* American Journal of Systems Science, 2015. **4**(1): p. 11–26.

2. Gordon, A.H., *THE PATIENT AS A PERSON.* Canadian Medical Association Journal, 1934. **31**(2): p. 191–193.

3. May, C. and N. Mead, *Patient-centredness: A history*, in *Ethical issues in general practice: Uncertainty and responsibility*, C. Dowrick and L. Frith, Editors. 1999. p. 76–91.

4. Engel, G.L., *The Need for a New Medical Model: A Challenge for Biomedicine.* Science, 1977. **196**(4286): p. 129–136.

5. *History of Planetree.* 1978; Available from: https://www.planetree.org/certification/about-planetree.

6. Mead, N. and P. Bower, *Patient-centredness: a conceptual framework and review of the empirical literature.* Social Science & Medicine, 2000. **51**(7): p. 1087–110.

7. Barry, M.J. and S. Edgman-Levitan, *Shared decision making—the pinnacle of patient-centered care.* New England Journal of Medicine, 2012. **366**(9): p. 780–781.

8. Balint, M., *The doctor, his patient, and the illness.* Lancet, 1955. **268**(6866): p. 683–8.

9. Jewson, N.D., *The Disappearance of the Sick-Man from Medical Cosmology, 1770–1870.* Sociology, 1976. **10**(2): p. 225–244.

10. Peabody, F.W., *Landmark article March 19, 1927: The care of the patient. By Francis W. Peabody.* JAMA, 1984. **252**(6): p. 813–8.

11. Elwyn, G., et al., *Shared decision making and the concept of equipoise: the competencies of involving patients in healthcare choices.* The British Journal of General Practice, 2000. **50**(460): p. 892.

12. Stewart, M., *Towards a global definition of patient-centred care.* British Medical Journal, 2001. **322**(7284): p. 444.

13. Barry, M.J. and S. Edgman-Levitan, *Shared decision making—The pinnacle patient-centered care.* 2012.

14. Stewart, M., et al., *Patient-Centered Medicine 3e Ebook: Transforming the Clinical Method* 2014: Radcliffe Publishing Ltd. Kindle Edition.

15. Elwyn, G., et al., *Shared decision making: a model for clinical practice.* Journal of general internal medicine, 2012. **27**(10): p. 1361–1367.

16. Aboumatar, H.J., et al., *Promising Practices for Achieving Patient-centered Hospital Care A National Study of High-performing US Hospitals.* Medical Care, 2015. **53**(9): p. 758–767.

17. Goyal, R.K., et al., *'A local habitation and a name': how narrative evidence-based medicine transforms the translational research paradigm. [Review] [74 refs].* Journal of Evaluation in Clinical Practice, 2008. **14**(5): p. 732–741.

18. Guastello, S. and K. Jay, *Improving the patient experience through a comprehensive performance framework to evaluate excellence in person-centred care.* BMJ Open Quality, 2019. **8**(4): p. e000737.

19. Bohren, M.A., et al., *The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review.* PLOS Medicine, 2015. **12**(6): p. e1001847.

20. Afulani, P.A., et al., *Person-centred maternity care in low-income and middle-income countries: analysis of data from Kenya, Ghana, and India.* The Lancet Global Health, 2019. **7**(1): p. e96–e109.

21. Gaillard, L.M., M.M. Shattell, and S.P. Thomas, *Mental health patients' experiences of being misunderstood.* Journal of the American Psychiatric Nurses Association, 2009. **15**(3): p. 191–199.

22. Fremont, A.M., et al., *Patient-centered processes of care and long-term outcomes of myocardial infarction.* Journal of General Internal Medicine. **16**(12): p. 800–8.

23. Peters, M., et al. *Patients' experiences of health and social care in long-term neurological conditions in England: a cross-sectional survey.* Journal of Health Services Research & Policy, 2013. **18**, 28–33 DOI: 10.1258/jhsrp. 2012.011176.

24. Brooks, F., et al. *Evaluation of services for children with complex needs: mapping service provision in one NHS Trust.* Primary health care research & development, 2013. **14**, 52–62 DOI: 10.1017/s1463423612000217.

25. Berntsen, G.R., et al., *A person-centered integrated care quality framework. A qualitative study of patients' evaluation of care in light of chronic care ideals.* BMC Health services research 2018(18): p. 1–15.

26. Mason, B., et al., *'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: Serial interviews with patients and carers.* BMJ Supportive and Palliative Care, 2016. **6**(1): p. 60–65.

27. Greenfield, G., et al. *Wake up, wake up! It's me! It's my life! Patient narratives on person-centeredness in the integrated care context: a qualitative study.* BMC Health Services Research, 2014. **14**, DOI: 10.1186/s12913-014-0619-9.

28. WHO. *Framework on integrated, people-centred health services. Report by the Secretariat.* 2016 08.08.2019]; 1–12]. Available from: Accessed at: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1

29. Sampath, B., et al., *Whole System Quality. A Unified Approach to Building Responsive, Resilient Health Care Systems. IHI White Paper.*, I.f.H. Improvement, Editor. 2021: Boston.

30. Rijken, M., et al., *How to improve care for people with multimorbidity in Europe?* 2017: World Health Organization, Regional Office for Europe.

31. American Geriatrics Society Expert Panel on Person-Centered, C., et al., *Person-centered care: A definition and essential elements.* Journal of the American Geriatrics Society, 2016. **64**(1): p. 15–18.

32. Coulter, A., et al., *Personalised care planning for adults with chronic or long-term health conditions.* Cochrane Database of Systematic Reviews, 2015(3): p. 1–129.

33. *Health Promotion Glossary*, W.H. Organization, Editor. 1998, World Health Organization.

34. Capozza, D., et al., *Dehumanization in medical contexts: An expanding research field.* TPM: Testing, Psychometrics, Methodology in Applied Psychology, 2016. **23**(4).

35. Agledahl, K., R. Førde, and Å. Wifstad *Clinical essentialising: a qualitative study of doctors' medical and moral practice.* Medicine, Health Care and Philosophy, 2010. **13**, 107–113 DOI: 10.1007/s11019-009-9193-z.

36. Sackett, D.L., et al., *Evidence-based medicine: what it is and what it isn't.* BMJ, 1996. **312**(7023): p. 71–72.

37. *Fragility, Conflict & Violence.* 2021; Available from: https://www.worldbank.org/en/topic/fragilityconflictviolence/overview#1.

38. Ware, N.C., et al., *Toward an understanding of disengagement from HIV treatment and care in sub-Saharan Africa: a qualitative study.* 2013. **10**(1): p. e1001369.

39. Christoff, K., *Dehumanization in organizational settings: some scientific and ethical considerations.* Frontiers in human neuroscience, 2014. **8**: p. 748.

40. Cassel, E.J., *The nature of suffering and the goals of medicine.* The New England journal of medicine, 1982. **306**(11): p. 639–645.

41. Haque, O.S. and A. Waytz, *Dehumanization in medicine: Causes, solutions, and functions.* Perspectives on psychological science, 2012. **7**(2): p. 176–186.

42. Entwistle, V.A., et al., *"The more you know, the more you realise it is really challenging to do": tensions and uncertainties in person-centred support for people with long-term conditions.* Patient Education and Counseling, 2018.

43. Olsen, C.F., et al., *What matters when asking, "what matters to you?"— perceptions and experiences of health care providers on involving older people in transitional care.* BMC health services research, 2020. **20**: p. 1–13.

44. Meadows, D.H., *Thinking in systems: A primer.* 2008: Chelsea green publishing.

45. Berwick, D.M., T.W. Nolan, and J. Whittington, *The Triple Aim: Care, Health, And Cost.* Health Affairs, 2008. **27**(3): p. 759–769.

46. Bodenheimer, T. and C.J.T.A.o. F.M. Sinsky, *From triple to quadruple aim: care of the patient requires care of the provider.* 2014. **12**(6): p. 573–576.

47. WHO, *The World Health Report 2000. Health Systems: Improving Performance.* 2000.

48. Pellegrino, E.D. and D.C. Thomasma, *The conflict between autonomy and beneficence in medical ethics: proposal for a resolution.* Journal of Contemporary Health Law & Policy, 1987. **3**: p. 23–46.

49. Berntsen, G.K.R., et al., *How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care.* BMJ Open, 2015. **5**(12): p. 1–8.

50. Bisognano, M. and D. Schummers *ESSAY Flipping healthcare: an essay by Maureen Bisognano and Dan Schummers.* BMJ, 2014. **349**, g5852 DOI: 10.1136/BMJ.g5852.

51. Kirkegaard, S., *On My Works as an Author – Chapter A2, translated by Howard V. Hong and Edna H. Hong.* 1859.

52. McBain, H., M. Shipley, and S. Newman, *The impact of self-monitoring in chronic illness on healthcare utilisation: a systematic review of reviews.* Bmc Health Services Research, 2015. **15**: p. 1–10.

53. Steventon, A., et al., *Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial.* BMJ: British Medical Journal, 2012. **344**: p. 1–15.

54. Pinnock, H., et al., *Systematic meta-review of supported self-management for asthma: a healthcare perspective.* Bmc Medicine, 2017. **15**: p. 32.

55. Henderson, C., et al., *Cost-effectiveness of telehealth for patients with long term conditions (Whole Systems Demonstrator telehealth questionnaire study): nested economic evaluation in a pragmatic, cluster randomised controlled trial.* BMJ, 2013. **346**.

56. Sorensen, K., et al., *Health literacy and public health: a systematic review and integration of definitions and models.* BMC Public Health, 2012(1): p. 80.

57. Du, S. and C. Yuan, *Evaluation of patient self-management outcomes in health care: a systematic review.* International Nursing Review, 2010. **57**(2): p. 159–67.

58. Zoffmann, V. and T. Lauritzen, *Guided self-determination improves life skills with type 1 diabetes and A1C in randomized controlled trial.* Patient education and counseling, 2006. **64**(1): p. 78–86.

59. Zoffmann, V., et al., *Translating person-centered care into practice: A comparative analysis of motivational interviewing, illness-integration support, and guided self-determination.* Patient Education and Counseling, 2016. **99**(3): p. 400–407.

60. Rollnick, S. and J. Allison, *Motivational interviewing*, in *The essential handbook of treatment and prevention of alcohol problems*. 2004, John Wiley & Sons, Ltd, West Essex. p. 105–116.

61. Vibeke, Z., H. Ingegerd, and K. Marit, *A Person-Centered Communication and Reflection Model: Sharing Decision-Making in Chronic Care.* Qualitative Health Research, 2008. **18**(5): p. 670–685.

62. Hughes, L.D., M.E. McMurdo, and B. Guthrie, *Guidelines for people not for diseases: the challenges of applying UK clinical guidelines to people with multimorbidity.* Age & Ageing, 2013. **42**(1): p. 62–9.

63. Muth, C., et al. *The Ariadne principles: how to handle multimorbidity in primary care consultations.* BMC Medicine, 2014. **12**, 1–11 DOI: 10.1186/s12916-014-0223-1.

64. *Multimorbidity: clinical assessment and management. Multimorbidity: assessment, prioritisation and management of care for people with commonly occurring multimorbidity.*, in *NICE guideline NG56, Methods, evidence and recommendations*. 2016, National Guideline Centre: National Institute for Health and Care Excellence, UK. p. 1–443.

65. Høyem, A., et al., *Keeping one step ahead: A qualitative study among Norwegian health-care providers in hospitals involved in care coordination for patients with complex needs.* International Journal of Care Coordination, 2018.

66. Weiner, S.J., et al., *Patient-centered decision making and health care outcomes: an observational study.* Annals of internal medicine, 2013. **158**(8): p. 573–579.

67. WHO, *People-centred and integrated health services: an overview of the evidence. Interim report*, in *Service Delivery and Safety, World Health Organization*. 2015: Geneva, Switzerland. p. 1–65.

68. Berntsen, G.K.R., et al., *The evidence base for an ideal care pathway for frail and multi-morbid elderly: A combined scoping review and systematic intervention review. .* J Med Internet Res, 2019.

69. Snowden, D.J. and M.E. Boone, *A leader's framework for decision making.* Harvard business review, 2007. **85**(11): p. 1–9.

70. Plsek, P.E. and T. Greenhalgh, *The challenge of complexity in health care.* BMJ, 2001. **323**(7313): p. 625–628.

71. Greenhalgh, T. and C. Papoutsi, *Studying complexity in health services research: desperately seeking an overdue paradigm shift.* BMC Medicine, 2018. **16**: p. 1–6.

72. Mendelson, A., et al., *The Effects of Pay-for-Performance Programs on Health, Health Care Use, and Processes of Care.* Annals of Internal Medicine, 2017. **166**(5): p. 341-+.

73. Stanowski, A.C., K. Simpson, and A. White, *Pay for Performance: Are Hospitals Becoming More Efficient in Improving Their Patient Experience?* Journal of Healthcare Management, 2015. **60**(4): p. 268–284.

74. Barr, P.J., et al., *The Psychometric Properties of CollaboRATE: A Fast and Frugal Patient-Reported Measure of the Shared Decision-Making Process.* Journal of medical Internet research, 2014. **16**(1).

75. Miller, S., B. Duncan, and J. Brown, *The Outcome Rating Scale: A Preliminary Study of the Reliability, Validity, and Feasibility of a Brief Visual Analog Measure.* Journal of Brief Therapy, 2003. **2**: p. 91–100.

76. Miller, S.D., et al., *Using formal client feedback to improve retention and outcome: Making ongoing, real-time assessment feasible.* Journal of Brief Therapy, 2006. **5**(1): p. 5–22.

77. *Outcome Rating Scale (ORS) & Child Outcome Rating Scale (CORS).* [cited 2022 12th Feb 2022]; Available from: https://www.corc.uk.net/outcome-experience-measures/outcome-rating-scale-ors-child-outcome-rating-scale-cors/.

78. Hatem, D. and E.A. Rider, *Sharing stories: narrative medicine in an evidence-based world*. Patient Educ Couns, 2004. **54**(3): p. 251–253.

79. Rockwood, K., B. Joyce, and P. Stolee, *Use of goal attainment scaling in measuring clinically important change in cognitive rehabilitation patients.* Journal of Clinical Epidemiology, 1997. **50**(5): p. 581–588.

80. Krasny-Pacini, A., et al. *Goal Attainment Scaling in rehabilitation: A literature-based update*. Annals of Physical and Rehabilitation Medicine, 2013. **56**, 212–230 DOI: http://dx.doi.org/10.1016/j.rehab.2013.02.002.

81. Paterson, C., et al. *Assessing patient outcomes in acute exacerbations of chronic bronchitis: The measure your medical outcome profile (MY-MOP), medical outcomes study 6-item general health survey (MOS-6A) and EuroQol (EQ-5D)*. Quality of Life Research, 2000. **9**, 521–527 DOI: 10.1023/a:1008930521566.

82. Ruta, D.A., et al. *A New Approach to the Measurement of Quality of Life: The Patient-Generated Index*. Medical Care, 1994. **32**, 1109–1126 DOI: 10.2307/3766320.

83. Kiresuk, T. and R. Sherman, *Goal attainment scaling: A general method for evaluating comprehensive community mental health programs.* Community Mental Health Journal, 1968. **4**(6): p. 443–453.

84. Rockwood, K., et al., *Responsiveness of goal attainment scaling in a randomized controlled trial of comprehensive geriatric assessment.* Journal of Clinical Epidemiology, 2003. **56**(8): p. 736–743.

85. Stratford, P., et al., *Assessing disability and change on individual patients: a report of a patient-specific measure.* Physiotherapy Canada, 1995. **47**(4): p. 258–263.

86. Chatman, A.B., et al., *The Patient-Specific Functional Scale: measurement properties in patients with knee dysfunction.* Physical Therapy, 1997. **77**(8): p. 820–829.

87. Westaway, M., P. Stratford, and J. Binkley, *The patient-specific functional scale: validation of its use in persons with neck dysfunction.* The Journal of orthopaedic and sports physical therapy, 1998. **27**(5): p. 331–338.

88. Kuspinar, A. and N.E. Mayo, *Do generic utility measures capture what is important to the quality of life of people with multiple sclerosis?* Health & Quality of Life Outcomes, 2013. **11**: p. 71.

89. Miller, E. and K. Barrie, *Personal outcomes. Learning from the Meaningful and Measurable project: Strengthening links between identity, action and decision-making.* 2016, Healthcare Improvement Scotland.

90. Berry, L.L., et al., *When Patients and Their Families Feel Like Hostages to Health Care.* Mayo Clinic Proceedings, 2017. **92**(9): p. 1373–1381.

91. Gibson, R.M., *Bridging the gap between rhetoric and reality: can the law enforce quality patient-centred care in Australia?* 2016.

92. Hsu, M.Y. and B. McCormack, *Using narrative inquiry with older people to inform practice and service developments.* Journal of Clinical Nursing, 2012. **21**(5–6): p. 841–849.

93. Tsianakas, V., et al., *Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both?* Bmc Health Services Research, 2012. **12**.

94. Miller, S.D. and B.L. Duncan, *Paradigm lost: From model-driven to client-directed, outcome-informed clinical work.* Journal of Systemic Therapies, 2000. **19**(1): p. 20–34.

95. Campbell, A. and S. Hemsley, *Outcome Rating Scale and Session Rating Scale in psychological practice: Clinical utility of ultra-brief measures.* Clinical Psychologist, 2009. **13**(1): p. 1–9.

96. WHO, *WHO Global Strategy on Digital Health 2020–2024.* 2019.

97. Were, M.C., C. Sinha, and C. Catalani, *A systematic approach to equity assessment for digital health interventions: case example of mobile personal health records.* Journal of the American Medical Informatics Association, 2019. **26**(8–9): p. 884–890.

98. Zanaboni, P., et al., *Patient Use and Experience With Online Access to Electronic Health Records in Norway: Results From an Online Survey.* Journal of medical Internet research, 2020. **22**(2): p. e16144.

Figures & Tables

Figure 1 – Page 15 – Patient-System meeting

Figure 2 – Page 16 – The Iceberg Model, Monat, J.P. and T.F. Gannon, *What is systems thinking? A review of selected literature plus recommendations.* American Journal of Systems Science, 2015. **4**(1): p. 11–26.

Figure 3 – Page 17 – The visible events of the health care system: The patient journey (PJ) arises at the intersections between the professionally defined care pathways (red) and the personal life pathway (blue) of the patient. The payer/regulator is an invisible but omnipresent partner, shaping the PJ through funding and regulations

Figure 4 – Page 21 – The new mental model: The overarching goal of the care system is to improve and maintain health, understood as a resource for "what matters" in the life of patients. Professionals serve "what matters". The system level, serves professionals.

Table 1 – Page 22 – The role changes that will ensue from a PCC mental model

Figure 5 – Page 33 – The four areas of complexity theory adapted from Snowden, D.J. and M.E. Boone, *A leader's framework for decision making.* Harvard business review, 2007. **85**(11): p. 1–9.

Table 2 – Page 36 – Key areas for consideration in the PCC care system

Figure 6 – Page 40 – The Person, the Journey, the Goal