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# Advancing towards the implementation of patient-centred care in Chile: An opportunity to effectively practice shared decision-making

## *Auf dem Weg zur Implementierung von patientenzentrierter Versorgung in Chile: eine Chance, partizipative Entscheidungsfindung wirkungsvoll in die Praxis umzusetzen*

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ABSTRACT

In Chile, local normative and guidelines place patient-centred care (PCC) as a desirable means and outcome for each level of health care. Thus, a definition of PCC is provided, and for the first time shared decision-making (SDM) is included as an intended practice. During the past five years the country has shown progress on the implementation of PCC. A large pilot study was conducted in one of the Metropolitan Health Services, and now the health authority is committed to escalate a PCC strategy nationwide. From the practice domain, most of the work is being placed on the training of health professionals. Patients' preparation for the clinical encounter is scarce, thereby limiting their potential to participate in their care. At the research domain, the country shows a strengthened agenda that has advanced from a diagnostic phase (including the exploration from social sciences) to a purposeful stage which involves the development of training programs, patient decision aids, international collaborations, and other PCC interventions. The country is now positioned to secure new initiatives to empower patients and allow them to take an active role, as a key component of PCC and SDM.

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ZUSAMMENFASSUNG

In den regionalen Richt- und Leitlinien gilt eine patientenzentrierte Versorgung („patient-centred care", PCC) auf allen Ebenen der Gesundheitsversorgung in Chile als erstrebenswertes Mittel und Ziel. Damit ist eine Definition von PCC gegeben, in der erstmals auch partizipativer Entscheidungsfindung (PEF) Raum gegeben wird. In den letzten fünf Jahren hat das Land Fortschritte bei der Implementierung von PCC erzielt. In einem der großstädtischen Gesundheitsversorgungszentren wurde eine große Pilotstudie durchgeführt, und nun sind die Gesundheitsbehörden entschlossen, die PCC-Strategie auf das ganze Land auszuweiten. Was den Praxisbereich betrifft, so liegt der Schwerpunkt hier auf der Ausbildung von Gesundheitsfachkräften. Eine Vorbereitung von Patienten auf den Arzt-Patient-Kontakt findet kaum statt, was den Möglichkeiten von Patienten, sich an ihrer Gesundheitsversorgung zu beteiligen, Grenzen setzt. Im Bereich der Forschung hat sich das Land eine ambitioniertere Agenda zum Ziel gesetzt, wobei wir von einer diagnostischen Phase (die auch sozialwissenschaftliche Untersuchungen einschließt) in eine zielgerichtete Phase eingetreten sind, welche die Entwicklung von Ausbildungsprogrammen, von Entscheidungshilfen für Patienten, internationale Kooperationen sowie andere PCC-Interventionen

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beinhaltet. Chile ist nun in der Lage, neue Patienten-Empowerment-Initiativen auf den Weg zu bringen und es – als Schlüsselkomponente von PCC und PEF – Patienten auf diese Weise zu ermöglichen, eine aktive Rolle einzunehmen.

## The Chilean healthcare system at a glance

Chile is considered one of the safest and most stable countries in the Latin American region. The country has reached a high level of development and is listed as a high-income country since 2014 [1]. This socioeconomic outlook has also brought new health challenges for the Chilean people. Non-communicable chronic conditions are affecting most of the population. It is estimated that three out of four Chileans are living with two or more chronic conditions [2–4], so the topic of multi-morbidity has taken the public health agenda. In addition to this, cancer is expected to overtake the first cause of death in this population within the next decade [5]. Thus, it is expected that with accelerated advances in cancer treatment, the cancer survivorship will continue to increase so cancer will add to the prevalence of chronic non-communicable diseases.

Over the last 40 years, the Chilean healthcare system has combined both public and private providers (FONAS and ISAPRE, respectively) and insurers [6,7]. Most of the population uses public health services (around 80%), and less than 5% reports no care provision. As the public sector is in high demand, waiting lists for specialists and health procedures (including surgeries, exams, etc.) nudge people to make out-of-pocket payments and access highly expensive private services [8]. Consequently, health inequalities rise with healthcare segregated and continuity of care challenged.

## The prosperity challenged by socio-political and health crises

The economic prosperity of the country has also involved a new phenomenon: the migratory flow. Since 2010 the country has experienced an increasing arrival of Latin Americans, coming predominantly from Venezuela, Perú and Haiti [9]. Many of them entered through unauthorised crossings. This unprecedent international migration has impacted the health system due to the difficulties informal migration places for people to access the healthcare services in comparison to Chilean citizens [10,11]. According to the Survey of National Economic and Social Characteristics (CASEN) in 2017, 15.8% of the migrant population was not affiliated to any health system (FONASA or ISAPRE) compared to 2.2% of Chileans [12]. Although efforts have been made to guarantee specific health benefits for the migrant population, this group still faces problems in accessing the health system [13]. Consequently, the problems in accessibility limit the participation of patients in their healthcare as well as the interaction between health personnel and migrants. Also, with an increasing number of marginalized and vulnerable migrant people, some of the key health achievements of the country could be jeopardize if the access gap remains, and no culturally competent healthcare is provided [14].

Additionally, the longstanding stability of the country has been questioned by its population. In October 2019, Chile experienced what has been called "the social explosion" (*el estallido social*). With the slogan "Chile woke up", a series of national protests took up the political, social, and health agenda, as the population showed discontent with the country's socioeconomic system of the last four decades. In regard to healthcare, during the protests the general demand was oriented to recognise patients' dignity within healthcare and secure access for all. The result of this social crisis is an ongoing development process of a new National Constitution, for which the Chilean population is waiting to know what will be guaranteed as a basic right to health.

The COVID-19 pandemic hit during the social-political instability across the country with rising health inequalities [15]. Consistent with other Latin American countries, during the first wave of the pandemic, the Ministry of Health focused on securing mechanical ventilators and in converting general inpatient beds into intensive care beds. The emphasis on highly specialised care created a sense of uncertainty in other fields, such as primary healthcare [16], which in turn promoted a curative approach to the sanitary crisis instead of implementing preventive measures. During 2021, health authorities focused on the securement of vaccines, placing the country in the world's top for vaccination coverage. However, essential health services unrelated to the coronavirus and linked to promotional and preventive actions (such as health controls for children and adolescents and people with chronic conditions) were irremediably postponed. This has a clear impact on the health of the population, evidencing a setback in some structural determinants such as access to health services. In addition, risk communication remains underdeveloped and ineffective as COVID-19 cases continue to increase and a new wave is currently affecting the population. As such, the management of the pandemic has been mostly focusing on the spread of the virus rather than on how people have been affected by this and what (active) role they could play to overcome this critical situation.

Together with the ongoing social uprising, the country has demanded a new political style. In March 2022 Gabriel Boric - the youngest president in the history of Chile - has taken power. Boric's health agenda proposes substantial changes in health in the medium and long term. First, the government has been self-defined as feminist, and special attention will be put to the creation of an Universal/Unified Health System, the promotion of dignified healthcare, and intercultural health approach, among other priorities [17].

## Legislative and normative milestones that promote patient-centred care (PCC)

### *A patient-centred health system*

Over the past 20 years Chile has declared a clear commitment to move healthcare towards PCC. The latest Health Reform sustained the health model for primary care on three pillars: comprehensive care, continuity of care, and patient-centred care [18]. Additionally, there is a legal mandate to promote patient's rights and participation in healthcare, by ensuring that clear, timing, and honest information is provided to patients so they can take an active role in their care.

Although PCC is a main attribute of the Chilean health model, it is unclear how it impacts on the effective participation of people and communities in their care or the policies that can affect their lives; which translates into a variability of clinical practice furthering inequities and diverse patient experiences [19]. However, the current model focuses on production goals that maintain a verticalized clinician-patient relationship, resulting in low participation rates and a disease-centred approach. This fragmentates care and affects patients' satisfaction [19]. This is particularly relevant for people living with multi-morbidities, as they need to access healthcare multiple times, with different health professionals, each

of them treating individual conditions [3]. This lack of comprehensive and patient-centred care influences quality of care and patient satisfaction.

The 2021 and 2022 Network Planning and Programming Guidelines [20] of the Ministry of Health have made explicit the need to break the administrative, institutional, and organizational fragmentation of the health sector; highlighting the priority to advance the integration of services and continuity of care. Thus, the Guidelines include as key actions a) to train health professionals in the value of patients' participation so they can promote it as a pillar of care and b) to place patients at the centre of services, by achieving continuity of care in health, anticipating harm, prioritizing vulnerable groups and respecting dignity and cultural diversity [21].

*Tackling multi-morbidity and cancer through patient-centred care and shared decision-making*

As mentioned above, multi-morbidity is affecting the majority of the population. People living with multi-morbidity are using a large part of the health services. As such, the capacity of the health system is at its limit [2]. It is estimated that the health system could only offer coverage to 36% of the population with multi-morbidity [22]. This number requires rethinking the way in which care is being delivered and the capacities that are generated in the patients so that they can make more efficient use of available resources. Considering the epidemiological profile of Chilean citizens, since 2021 the Ministry of Health has promoted a national policy to manage multi-morbidity [4]. This has been summarized in a national patient-centred comprehensive care strategy with emphasis on the multi-morbidity that makes explicit the need to have adequate (professional) training in patient-centred care, management of multi-morbidity and use of decision support technologies [21]. In this national document, PCC is defined as a method through which "health professionals address four components when approaching patients: 1) illness, health and disease; 2) approach the person as a whole; 3) reach a common agreement based on the definition of problems, objectives and roles; and 4) develop the relationship between the health team and the patient". For the first time in the country, the term shared decision-making (SDM) is used as part of a governmental document. SDM was defined there as "a process in which the health team and the patient share the best available evidence when faced with the task of making decisions, and where people are supported to consider options in order to identify their informed preferences". This practically is linked to a collaborative and consensus healthcare plan, as a means and a desirable outcome for PCC in the context of multi-morbidity [3,4].

Pilot project experiences at the South-East Metropolitan Health Service (SEMHS) have implemented the strategy of PCC for multi-morbidity. Based on these experiences, the escalation model for PCC across the country has been set-up and includes [3]:

1) change management approach, as this new model of care is considered a complex intervention and consequently health services and providers must prepare to shift towards PCC;
2) risk stratification, so people are individually assessed and their risk level is estimated so comprehensive care can be tailored and offered to them;
3) integral system for health records and health appointments, including longer health appointments that could now last 60 minutes per patient;
4) practice of PCC, so health teams reinforce their companionship role, and act in an interdisciplinary manner, promote patient involvement and act based on risk stratification; and
5) continuity of care, using remote follow-up and transition of health care across the different levels of care within the system.

As a starting point, the Division of Primary Care at the Ministry, in collaboration with the SEMHS and the Health Innovation Centre at the Pontificia Universidad Católica de Chile, has set up a series of online trainings for health providers. The trainings reinforced health professionals' skills to care for people with chronic conditions, based on patient-centred interventions. To date 300 health centres have participated in this training (reaching over 2,500 health providers) [23]. However, no strategy has been set up to date to activate patients and consequently support them to take an active role in their healthcare [19]. This is critical to ensure the effectiveness of this strategy. Qualitative reports indicate that Chilean patients tend to prefer a passive role in healthcare, as long as they feel they can trust in the health professionals [24].

Considering the relevance that cancer-related mortality is having in the country, a National Plan for Cancer (2018–2028) was released. The Plan considers important strategies for prevention and treatment, including to operationalize the fundamental principles stated for primary health care (applicable to all levels of care). The Plan includes PCC as a foundation for all actions related to cancer care [25]. The way this will be operationalised is still unknown, as limited local evidence has been produced around PCC and cancer care.

Finally, the Ministry of Health is still working on the National Health Plan for the decade 2021–2030. Preliminary announcements of the Plan indicate that a special focus will be given to social participation in healthcare and quality of healthcare [26]. It is expected that this new Plan gives health professionals clearer guidelines for patient involvement and engagement in healthcare, as this was scarcely achieved in the previous Plan 2011–2020 [6,27].

## Patient and public involvement

Despite the fact that Chile has made efforts to promote social/community participation at macro and meso levels in health (e.g. through mechanisms such as User Councils or Participatory Budgets), these have been insufficient to transform into real and effective participation that can impact clinical encounters (micro level) [6].

However, during the last decade patients' organisations have increased their visibility in decision-making in the health system [28], and efforts have been made to promote their institutionalization through the Citizens' Commission for System Oversight and Control and the Prioritized Recommendation Commission [29]. Additionally, local researchers have proposed some guidelines to orientate patient involvement in the decision-making process of health coverage [30].

During this five-year period, the Chilean College of Physicians has also visualized the importance of social participation in health. Through the College's scientific journal, a special issue was released in 2018 to discuss the state-of-the-art of social participation in healthcare. Specific to participation in decision-making, two main findings are: 1) to establish formal spaces for participation of the population and empower its representatives [31]; 2) to train health professionals in how to communicate effectively with patients and promote their involvement in shared decision-making [32].

## Research agenda on PCC/SDM

The country has made some progress in the generation of local evidence related to PCC and SDM. Although the National Agency for Research and Development (ANID) has no special call for such projects, some research teams have secured funding to advance this field.

**Table 1**
Research on SDM conducted in Chile 2016–2025.

| Research Team | Name | Years | Project's publicly available information/Publications | Funding body |
|---|---|---|---|---|
| Peña y Lillo *et al.* | Information environments on covid-19 and adoption of preventive behaviors in the general population and risk groups | 2020 | https://eiscovid.cl/ [37] | ANID-COVID |
| Cerda *et al.* | Selfcare management and access to health benefits for people with risk factors associated with lifestyle during the COVID-19 pandemic | 2020 | Not found [38] | ANID COVID |
| Weber *et al.* | Integrated information system for home monitoring of COVID-19 patients in health services | 2020 | https://www.sistemaspublicos.cl/gproyecto/covid0251/ [38] | ANID COVID |
| Montenegro *et al.* | A rapid assessment of perceptions of health workers and users about health care in the context of the COVID-19 pandemic in Chile | 2020 | Published [39] | ANID COVID |
| Bravo *et al.* | Development of a best practice guideline for risk communication associated with the COVID-19 pandemic | 2020–2022 | www.comunicacionderiesgo.cl [40] | ANID-COVID |
| Pedrero *et al.* | Development of an instrument to measure cultural competence in Chilean health workers | 2016–2018 | Published [14] | FONIS |
| Vera-Calzaretta *et al.* | Adaptation and validation of the new vital sign instrument for health literacy in chronic primary care patients | 2017 | Not found [41] | FONIS |
| Bravo *et al.* | Patient decision aids for breast cancer screening in primary healthcare | 2018–2022 | www.mimamografia.cl [42] | FONIS |
| Bravo *et al.* | Factors influencing the implementation of shared decision making: the case of breast cancer treatment in Chile | 2022–2025 | Ongoing [43] | FONDECYT |
| Dois *et al* | Autonomy as a patient-centred care experience in primary care | 2022–2023 | Ongoing [44] | Seed fund Pontificia Universidad Católica de Chile |
| Rojas *et al.* | A collaborative computer-assisted cognitive-behavioral educational and psychological treatment for depressed patients with chronic disease at primary care | 2018–2022 | Published [45–47] | FONDECYT |
| Soto *et al.* | Strengthening of Patient-Centered Care training in undergraduate health programs at the UC Faculty of Medicine | 2022–2023 | Ongoing [48] | Seed fund Pontificia Universidad Católica de Chile |

For the purpose of this article, we conducted a search in the ANID platform, specifically in the National Fund for Health Research (FONIS), the National Fund for Scientific and Technological Development (Fondecyt) and the COVID-19 special call to identify projects that could contribute to PCC and SDM in Chile. Table 1 summarises the projects and provides information about their available findings.

Most of the projects are still being developed or have no publicly available results. However, we would like to highlight some efforts that could bring PCC and SDM to the next level in the country.

1) The Centre of Health Innovation at the Pontificia Universidad Católica de Chile has set up a collaboration with the Southeast Metropolitan Health Service to pilot the "Patient-Centred Model of Care" (MACEP). MACEP is a complex health intervention that reorganizes health services and teams around patients. Its central elements are: patient stratification by complexity, support for self-management, participation and shared responsibility, continuity of care and case management. Based on over 32,000 patients followed for up to three years, there have been significant findings including decreased mortality, hospitalizations, hospital stay and emergency consultations [23,33]. The qualitative evaluation of health providers has shown favourable changes in the services offered that would positively affect the results of health and patients satisfaction [22].
2) An interdisciplinary team is currently conducting a randomised control trial to assess the effectiveness of the first patient decision aid on breast cancer screening in the country. The study is recruiting women nationwide and involves the exploration of barriers and facilitators for the adoption of patient decision aids, that could inform future efforts to implement them in routine care (Trial registration: NCT04948983 at ClinicalTrials.gov)
3) The Millennium Nucleus Center Authority and Power Asymmetries [34], an interdisciplinary research centre, is undertaking research to better understand the role of power imbalance in healthcare and how the figure of medical authority could affect the democratization of the clinical encounter.
4) An international collaboration has been established with researchers in Germany. The team has secured a three-year grant to exchange best practices in the implementation of and training in PCC. The project aims at building an international community of practice in this topic [35].
5) Researchers in Canada have established an international collaboration with representation from Chile. The team has secured a two-year grant to update the Cochrane review of patient decision aids, conduct a network meta-analysis, and use findings to update the International Patient Decision Aid Standards criteria [36].

## Conclusion

The country has demonstrated an enduring commitment to moving from a biomedical to a patient-centred approach. Current guidelines are focusing on the most predominant illness, proposing a model of care that places patients at the centre, and explicitly identifies the importance of involving patients in shared decision making. Progress has been made in terms of health professionals' training and person-centred strategies for multimorbidity. Also, it is particularly relevant that cancer care is identified as a priority for considering patients' preferences and values. Thereby indicating a new research and clinical agenda.

However, to date no national strategy is focusing on the preparation of patients so they can have an active role in healthcare.

Since the 2017 article on the state of SDM within Chile, [6] there has been progress in the research agenda with advancements from a diagnosis stage to proposed interventions that need to be evaluated in this Chilean context. Furthermore, findings are expected to generate evidence in support of interventions to facilitate the practice of PCC and SDM in Chile.

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## Conflicts of interest

The authors declare that there is no conflict of interest.

## CRediT author statement

Paulina Bravo: Conceptualization, Formal analysis, Methodology, Writing - original draft, Writing - review & editing, Funding acquisition. Angelina Dois: Formal analysis, Writing - original draft, Writing - review & editing. Alejandra Martínez: Formal analysis, Writing - original draft, Writing - review & editing. Marcela González-Agüero: Writing - review & editing. Gabriela Soto: Writing - review & editing. Andrea Rioseco: Writing - review & editing. Solange Campos: Writing - review & editing. Claudia Bustamante: Writing - review & editing. Irma Vargas: Writing - review & editing. Dawn Stacey: Writing - review & editing.

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