

## Original research

# User participation in clinical decision-making in primary health care in Chile\*

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**ABSTRACT**

**Objective.** Describe users' experience with participation in clinical decision-making at Centros de Salud Familiar [Family Health Centers] (CESFAM) in the primary health care (PHC) system.

**Methods.** Qualitative descriptive study. Focus groups made up of CESFAM users were held in southeastern Santiago, Chile, and the information was thematically analyzed using ATLAS.ti version 6® software.

**Results.** Five focus groups were held ( $n = 41$ ). The main themes that emerged from the discussions were the passive role of users in decisions and delegated decision-making, based on their trust in the health professional. Users' passive role limits their opportunities for participation in clinical decision-making, ceding power to the health professional. However, establishing a therapeutic partnership allows users to feel that they are being treated as unique individuals whom the professional listens to and respects, ensuring that the decisions of the health team can be trusted, since they look out for the users' real interests.

**Conclusion.** Users' participation in clinical encounters is still limited in Chile. However, bolstering that participation is essential for increasing user satisfaction and promoting people-centered care.

**Keywords**

Primary health care; community participation; decision-making; Chile.

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There is worldwide interest in actively involving people in health issues, respecting users' right to have their preferences considered (1) and including them in the search for therapeutic options to maintain a better quality of life and well-being (2–5).

The Declaration of Alma-Ata stresses the importance of individual and community participation, affirming that “people have the right and duty to participate individually and collectively in the planning and implementation of

their health care” (6), linking people's right to health with their right to participate in decisions that affect their lives (7). Therefore, promoting people's health means providing them with the resources they need to exercise greater control over their health (8).

The Chilean government has shown steady progress in this area. The strengthening of primary health care (PHC) in the country echoes the Declaration's call to promote the PHC strategy worldwide as a way to improve people's conditions and

quality of life (9). Chile's current *Modelo Integral de Salud Familiar y Comunitario* [Family and Community Comprehensive Health Model] (MAIS) is aligned with international efforts to involve people in their health care, advancing from a paternalistic model that places users in a passive position towards a participatory approach (1). In the last decade, Chile has focused on promoting users' active role in health management, involving them at different levels, from community advisory processes (e.g., in developing the Health Objectives for the Decade) to a role in government planning and evaluation (e.g., participatory budgeting in the health services) (10, 11).

Under MAIS, all work by health teams is guided by three core principles of care: person-centered, continuous, and comprehensive (12). The person-centered care approach considers users to be co-responsible for their care, in collaboration with health teams. For this reason, users need to receive adequate information to provide active and informed input into decision-making related to their care, and to feel that they are being treated decently (13). Moreover, Chile's *Ministerio de Salud* [Ministry of Health] has called for promoting people's participation as a basic element of user satisfaction, quality of care, and ethical professional practice (2, 3). This is backed by Chilean legislation on people's rights and duties as regards health, which recognizes users' dignity and autonomy in the decisions related to their care (2); moreover, the Strategic Health Plan for the Decade states that "there is no better physician than oneself" (3).

All of this suggests bright prospects for promoting user participation in health encounters. However, despite this commitment, Chile still lacks specific strategies to operationalize this user participation approach in clinical decisions (14), nor has there been an analysis of users' participation level in health decision-making. The present article describes the experience of participation in PHC clinical decisions from the perspective of users of *Centros de Salud Familiar* [Family Health Centers] (CESFAM).

## MATERIALS AND METHODS

A qualitative study was conducted, comprising focus groups with CESFAM users in Santiago, Chile. Focus groups are a research tool that, through a group

interview, enables members to interact so that accounts of participants' different experiences can be collected. The researcher acts as moderator, asking questions, keeping the conversation going, and encouraging members to participate (15). From this rich interaction, the researcher can collect valuable information, such as participants' anecdotes, observations, and experiences, providing understanding of the phenomenon under study (15, 16).

## Participants

The participants were CESFAM users from two *comunas* (Chile's smallest administrative subdivision) from south-eastern Santiago. The information was collected between January and May 2015, through convenience sampling, inviting users who had presented at the CESFAM during the recruitment and snowball phase, in which participants were asked to invite other users from their network of contacts who could potentially be interested in taking part in the study. The inclusion criteria were people over 18 years of age, users of the same CESFAM during at least two years, who were free of any disability or severe illness that could impede adequate understanding of the questions and the expression their opinions or wishes.

## Information analysis

Audio recordings and verbatim transcripts were made of the focus groups to provide researchers with in-depth access, for information and analysis. An interview script was used, drawn up with the available evidence, which was subjected to content validation by experts (available from the authors upon request). The criterion for conclusion was theoretical saturation. A thematic analysis was conducted, assisted by the software ATLAS.ti version 6®. The process of analysis included these steps (17):

- 1) Familiarization with the information: Three researchers collected information and the transcriptions were made by a research assistant, supervised by the researchers;
- 2) The researchers made a selection of relevant data (information extracts) which helped them to understand the dynamics of phenomenon of health decision-making;

- 3) The researchers assigned codes to the information extracts that were helpful for understanding the phenomenon;
- 4) The codes were grouped into patterns or subjects that are part of the meaning of the phenomenon and help describe it;
- 5) An exhaustive description was made of the nature of users' participation in health decision-making.

The study had the approval of the *Comité Ético Científico de la Facultad de Medicina de la Pontificia Universidad Católica* [Scientific Ethics Committee of the Medical School of the Pontifical Catholic University] of Chile, and of the *Comité de Ética del Servicio Metropolitano Sur-Oriente* [Ethics Committee of the Metropolitan South-East Service]. The researchers conducted the informed consent process in order to promote user participation in the project, as well as an understanding of its associated risks and benefits. All the participants signed the informed consent document. The information was processed anonymously and participants' sensitive data were stored separately from the recordings, transcripts, and consent forms.

## RESULTS

Five focus groups were conducted, with 10 men and 31 women. The average age was 43.8 years (ranging from 18–78). All were users of the same CESFAM for an average of 10.8 years.

Of the total, 92.7% regularly underwent health checkups, and 29.2% were regularly involved in other activities carried out by the center.

## Main emerging themes

After a rigorous analysis, patterns were identified in the information, with two themes emerging that characterized users' participation in health decisions (Table 1).

### Passive role of users in decision-making

The participants identified zero opportunities for participating in the decisions related to their health, such as choosing the professional who treats them, or the treatment to address their health problem.

**TABLE 1. Emerging themes and subthemes that characterized Chilean users’ participation in health decision-making**

Subject	Subtopic
Passive role of users in decision-making	Lack of user participation: without opportunities to contribute, and centered on a single health problem The professional makes the decisions: without user participation, and sometimes not very effective
Delegated, trust-based clinical decisions	Effective communication: language that enables users to understand, and that shows interest on the part of the health professional Empathetic relationship: makes users feel unique and well cared for by professionals

Table by the authors, based on study results.

From these users’ perspective, health care is seen as a space in which there are limited possibilities for involvement and participation. Thus, during therapeutic encounters they feel that they should limit themselves to solving only one health problem (which is often not the most important one they face) and avoid referring to other situations that could be bothering them. In this scenario of passivity, users are not able to identify opportunities for participating in clinical decisions.

*He [the physician] told me, “I’m the doctor, and I’m in charge here”. (Man 1)*

*The doctors don’t talk to you very much, and if you want to talk about more things, they just want to stick to a single topic, nothing else. (Woman 1)*

*I said [to the physician], “My head hurts,” [and he said] “Oh, your head hurts? Then take an aspirin, buddy.” [Then I said to him] “But doctor, my nail hurts, too,” [and he replied] “Go out there and ask for an appointment next week for me to take a look at your nail.” (Man 2)*

Users also reported that in health care it is the professional who makes the clinical decisions, including everything from the health problem to be treated during the visit to the treatment that the user should have. According to these participants, such decisions are often incorrect, as they do not solve their problems.

*Doctors, like she just said, they don’t look at you – they come in and write stuff down. They see you for three minutes if you’re lucky, and then you’re out. But the solution is never the one you need. (Woman 3)*

*Another doctor saw me and [said to me] “Nah, it’s normal, it’s normal, take a paracetamol” and so on and so forth.*

*But you don’t know what to do, because the knee pain just keeps getting worse. (Woman 4)*

**Delegated, trust-based clinical decisions**

Users recognized that most decisions are taken by their health professionals. They positively assessed establishing a therapeutic partnership before decisions are made, through clear and effective communication and showing interest in their problems, which makes it possible for them to trust the professional’s judgement.

In order to understand the decision made by the professional, participants said that they need to have their health problem and treatment alternatives explained to them in everyday language. Furthermore, they highlighted the crucial importance of ongoing communication with health professionals in order to feel heard and respected.

*Because I want them to speak to me in plain Spanish, and not all this “blah, blah blah”. (Woman 5)*

*I wish the doctor would listen, that we could tell him everything that’s happening, because sometimes you have so many unasked questions and wind up going home with the same thing, and just don’t know. (Women 6)*

For the participants, it is essential that professionals make them feel unique, and show genuine concern for what is distressing them. This would enable them to believe that the decisions made by the professionals have the users’ best interests at heart.

*Because if a doctor asks you things like, “Do you have any questions? Does it hurt anywhere? Have you ever felt anything like this before?” What I mean is,*

*he [the physician] was asking me, it wasn’t just me telling him, oh, I’ve got this or that, he was the one asking the questions... that’s more personal, it makes you feel cared for, that someone is looking you in the eye. (Man 3)*

*The fact that they listen to you, that they give you advice, that they pay more attention to you—you’re not just another patient, or a number. (Woman 7)*

**DISCUSSION**

This article presents the experience of participation in clinical decision-making from the perspective of CESFAM users in the southeastern area of Santiago. Users’ passive role in clinical consultations limits their opportunities for participating in health decisions, leaving all the power in the hands of health professionals. However, an effective therapeutic relationship enabling them to feel treated as unique individuals who are heard and respected assures them that the decisions taken by the health team are truly looking after their interests.

Person-centered care, understood as strengthening shared responsibility of care, has significant impact on user satisfaction, on medium- and long-term health outcomes, and on organizing and coordinating health providers’ services, leading to better quality of care and a reduction in the overall cost of care by avoiding excessive use of health services and professionals’ time (18–21). Moreover, it has the potential to organize health care and enable users to experience transparent, individualized, respectful, decent care, with the opportunity to participate in all decisions on health matters. This improves compliance and promotes responsibility for their state of health (21, 22), and has a direct impact on users’ perception of the care they receive.

Participants’ experience in terms of trust-based decision-making coincides with what has been considered “successful care” in other countries, where communication, personalized care, and empathy are highlighted as the principal characteristics of good health care (23). The results presented in this article are consistent with those obtained by a group of Chilean researchers who found that only 56.1% of users perceived that physicians are always or almost always



concerned with them as individuals—a percentage that dropped to 46.3% in the case of nurses. The same study showed users' perception regarding the opportunity to give their opinion and discuss their health with the staff at health centers. Only 52% of users said they could always or almost always give their opinions about the treatment prescribed to them, and 26.5% said that they could never or almost never give their opinions (24). These results clearly show noncompliance with current legislation, since the Law on Health Care Users' Rights and Duties (Law No. 20,584) guarantees decent treatment and timely information, which should be translated into a process of effective communication between health professionals and users. This reported lack of opportunities for participation indicates that although Chile has moved forward in terms of community participation in health, promotion of an active role on the part of users in their clinical encounters is still limited (14). Researchers have reported that even providing information does not enable users to play a more active role, because the power imbalance can only be corrected when the health system makes it possible for professionals as well as users to be prepared to assume a collaborative and horizontal role (25, 26).

The strength of this study is based on its contribution to the limited local literature that examines users' role in clinical decision-making. However, these results should be considered with caution, since it is also important to consider the difficulties involved in setting up MAIS in Chile—related to the fact that although its overall foundations and strategies give special importance to the shift towards a mostly participatory model of care, its recent focus has

been curative, ensuring compliance with the requirements of the Explicit Guarantees System. With this approach, therapeutic activities revolve around disease and leave the preventive, health-promoting, user-centered component somewhat uncertain and subject to the commitment of individual health teams—which tend to focus on meeting ministerial targets to ensure financing for their health centers. Therefore, the regulations in force have reduced variations in MAIS implementation nationwide, which makes it more difficult to compare practices and evaluations from different PHC centers. For this reason, any comparison or generalization should consider the specific characteristics of this study's participants. Methodologically speaking, this study only used focus groups to explore participation in decision-making, which could limit understanding of the phenomenon. Considering that participation is, by definition, an interactive process, it would seem necessary to incorporate other tools for collecting information, such as individual interviews with key stakeholders (e.g., users, professionals, or policy decision-makers), and the observation of clinical consultations.

Future research could utilize measurements of user participation in clinical decision-making and examine, in addition, the perspective of professionals with regard to promoting user participation in clinical consultations. This would make it possible to examine the level of convergence and divergence of different actors (27) concerning users' role in health decision-making, opportunities to take up this role, and the level of training necessary to promote it among users, professionals, and others in the health system.

## CONCLUSIONS

The participation of Chilean PHC users in clinical decisions remains limited. According to the experience of this study's participants, professionals still hold the power, but personalized and empathic treatment helps users trust their judgment and decisions. Promoting user involvement is essential to increase satisfaction and promote person-centered care. From the viewpoint of the Alma-Ata Declaration, capacity-building is important in order for people to assume proper responsibility in taking care of their own health. PHC represents users' point of entry to the health system and it can offer a model for how users can interact with professionals and their role in that interaction. Therefore, implementing strategies to promote participation at this level of care is essential to generating a shift in the health model towards one that is more democratic and inclusive.

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## REFERENCES

1. Elwyn G, Tilburt L, Montori V. The ethical imperative for shared decision-making. *European Journal for Person Centered Healthcare*. 2013;1(1):129–31.
2. Ley N° 20.584. Regula los derechos y deberes que tienen las personas en relación con acciones vinculadas a su atención en salud, 2012.
3. Ministerio de Salud de Chile. Estrategia nacional de salud para el cumplimiento de los objetivos sanitarios de la década 2011–2020. Chile, 2010.
4. Bravo P, Contreras A, Perestelo-Pérez L, Pérez-Ramos J, Málaga G. En busca de una salud más participativa: compartiendo decisiones de salud. *Revista Peruana de Medicina Experimental y Salud Publica*. 2013;30:691–7.
5. Salzburg Global Seminar. Salzburg statement on shared decision making. *BMJ*. 2011;342.
6. Organización Mundial de la Salud OMS. Declaración de Alma-Ata. En: Conferencia Internacional sobre Atención Primaria de Salud, Alma-Ata Ginebra 1978 [cited 2018 05 enero]. Disponible en: <http://whqlibdoc.who.int/publications/9243541358.pdf>
7. Organización Mundial de la Salud (OMS). Informe sobre la salud en el mundo - Cambiemos el rumbo de la historia 2004. Disponible en: <http://www.who.int/whr/2004/chapter3/es/> Acceso el 8 de enero de 2018.
8. Organización Mundial de la Salud (OMS). Carta de Ottawa para la promoción de la salud. Primera conferencia internacional en promoción de salud 1986. Disponible en: <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/> Acceso el 8 de enero de 2018.

9. Organización Panamericana de la Salud (OPS). Hacia un modelo de atención integral a la salud basado en la Atención Primaria de Salud. Washington D.C.: OPS; 2012.
10. Delamaza G. Enhancing democracy: public policies and citizen participation in Chile. New York: Berghahn Books; 2015.
11. Bravo P, Cabieses B, Bustamante C, Campos S, Stacey D. Shared decision making in Chile: Supportive policies and research initiatives. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*. 2011;105(4):254–8.
12. Ministerio de Salud de Chile (MINSAL). Orientaciones para la implementación del Modelo de Atención Integral de Salud familiar y comunitaria. Chile: MINSAL; 2013.
13. Pérez V, Pezoa M. ¿Qué es “trato digno” para los pacientes? Elementos que componen el trato digno. Informe global. Superintendencia de Salud Chile, Departamento de Estudios y Desarrollo; 2013.
14. Bravo P, Dois A, Cabieses B, Bustamante C, Campos S, Stacey D. Patient-centred care and shared decision making in Chile: Rising momentum for progress and implementation in clinical practice. *Z Evid Fortbild Qual Gesundhwes*. 2017;123–124:28–31.
15. Wilkinson S. Focus group research. En: Silverman D, editor. *Qualitative research: theory, method and practice*. London: Sage; 2004:177–99.
16. Morgan DL. Focus group as a qualitative research. 2nd ed. London: Sage; 1997.
17. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
18. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med*. 2000;51(7):1087–110.
19. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, et al. The impact of patient-centered care on outcomes. *The Journal of Family Practice*. 2000;49(9):796–804.
20. Kitson A, Marshall A, Bassett K, Zeitz K. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*. 2013;69(1):4–15.
21. Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. *MCCR*. 2013;70(4):351–79.
22. Dois Castellón A, Contreras Mejías A, Bravo Valenzuela P. Características y atributos de la atención centrada en el usuario: perspectiva de usuarios y profesionales. *Atención Primaria*. 2017;49(1): 58–60.
23. Bensing JM, Deveugele M, Moretti F, Fletcher I, van Vliet L, Van Bogaert M, et al. How to make the medical consultation more successful from a patient's perspective? Tips for doctors and patients from lay people in the United Kingdom, Italy, Belgium and the Netherlands. *Patient Education and Counseling*. 2011;84(3): 287–93.
24. Segovia I, Campodónico L, Contreras R, Quevedo F. Evaluación del impacto del modelo de salud familiar en la salud y en la satisfacción usuaria. 2010.
25. Joseph-Williams N, Edwards A, Elwyn G. Power imbalance prevents shared decision making. *BMJ*. 2014;348:3178–81.
26. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient education and counseling*. 2014;94(3): 291–309.
27. Menéndez E. El punto de vista del actor: homogeneidad, diferencia e historicidad. *Relaciones*. 1997;67:31–62.

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## RESUMEN

### Participación de los usuarios en las decisiones clínicas en la atención primaria de salud en Chile

**Objetivo.** Describir la experiencia de participación en las decisiones clínicas desde la perspectiva de usuarios de Centros de Salud Familiar (CESFAM) de la Atención Primaria de Salud (APS).

**Métodos.** Estudio de diseño cualitativo descriptivo; se realizaron grupos focales con usuarios de CESFAM del área sudeste de Santiago, Chile, y análisis temático de la información utilizando el programa ATLAS.ti versión 6®.

**Resultados.** Se realizaron cinco grupos focales (n = 41). Los principales temas emergentes fueron el rol pasivo de los usuarios en las decisiones y la toma de decisión delegada, basada en la confianza en el profesional. El rol pasivo de los usuarios limita las oportunidades de participación en las decisiones clínicas y mantiene el poder en los profesionales de la salud. A pesar de ello, el establecimiento de una alianza terapéutica les permita sentirse tratados como personas únicas, escuchados y respetados por los profesionales, lo que asegura que las decisiones tomadas por el equipo de salud son confiables, pues velan por sus reales intereses.

**Conclusión.** La participación de los usuarios en los encuentros clínicos es aún escasa en el país. Sin embargo, potenciar esta participación es esencial para aumentar la satisfacción usuaria y promover un cuidado centrado en la persona.

## Palabras clave

Atención primaria de salud; participación de la comunidad; toma de decisiones; Chile.

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**Participação dos  
usuários nas decisões  
clínicas na atenção primária  
à saúde no Chile**

**RESUMO**

**Objetivo.** Descrever a experiência de participação nas decisões clínicas dos usuários dos Centros de Saúde Familiar (CESFAM) de atenção primária à saúde.

**Métodos.** Estudo qualitativo descritivo conduzido em grupos de discussão formados por usuários dos CESFAM da região sudeste da cidade de Santiago, no Chile. Foi realizada uma análise temática das informações com o uso do programa de software ATLAS.ti® versão 6.

**Resultados.** Foram formados cinco grupos de discussão (n = 41). Os principais tópicos abordados foram o papel passivo dos usuários nas decisões e a tomada de decisão delegada aos profissionais na base da confiança. O papel passivo restringe as oportunidades de participação dos usuários nas decisões clínicas e mantém o poder nas mãos dos profissionais da saúde. Apesar disso, ao ser criada uma aliança terapêutica, os usuários se sentem tratados como indivíduos únicos que são ouvidos e respeitados pelos profissionais, o que assegura que as decisões tomadas pela equipe de saúde sejam confiáveis porque protegem os reais interesses dos usuários.

**Conclusão.** Os usuários ainda têm pouca participação nas interações clínicas no Chile. Porém, é fundamental reforçar esta participação para melhorar a satisfação do usuário e promover uma atenção mais centrada na pessoa.

**Palavras-chave**

Atenção primária à saúde; participação da comunidade; tomada de decisões; Chile.

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