

RESEARCH ARTICLE

# Improving access and quality of primary healthcare through women and adolescents' user committees: A mixed-methods case study in Kinshasa, Democratic Republic of the Congo

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**Abstract**

**Background:** Patient engagement is seen as a fundamental strategy for achieving quality patient-centred care, especially in community-based primary healthcare. Despite growing interest in patient engagement in Sub-Saharan Africa, few patient engagement initiatives have been identified, and those often are limited to lower levels of engagement, in participation in health research or in health system improvement. With the aim of giving a voice to under-represented community groups in healthcare governance, the *Access to Health services in Kinshasa (ASSK)* project supported the implementation of primary health services user committees in the Democratic Republic of the Congo, designed to enable the representation of two user groups with specific unmet sexual and reproductive health (SRH) needs: women and adolescents.

**Aims and Methods:** Using a mixed-method case study design combining quantitative secondary data (from the national health management information system—DHIS2) and qualitative data from two research World Café (WC1: Women user committees (WUC)  $n = 55$ ; WC2: Adolescents

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user committee (AUC)  $n = 63$ ), this paper looks at the implementation facilitators and barriers, and at the results of this initiative.

**Results:** Women and adolescent members of the user committees highlighted that their participation resulted in increased knowledge of SRH and their related rights, as well as in their 'soft skills' such as communication and leadership. In addition, participants reported greater transparency and accountability on the part of the community primary health centres (e.g. by displaying fees for procedures to counter over-billing). Ultimately, WUC and AUC were associated with improved health practices in the community such as increased use of SRH services (increase of 613% for Makala and 160% for Maluku II), including adolescent family planning (increase of 320% for Makala and 12% for Maluku II) and assisted childbirth for women 15–49 years old (increase of 283% for Makala and 23% for Maluku II).

**Conclusions:** Patient user committees for specific marginalised or under-represented groups appear to be an effective way of improving the quality of primary health care services. Further research is needed to better understand how to maximise its potential.

#### KEYWORDS

adolescents, patient engagement, sexual and reproductive health, Sub-Saharan Africa, user committees, women, World Café

#### Highlights

- User committees for marginalised or unrepresented groups in official bodies are an effective way for them to make their voices heard and influence health services to take their specific needs into account.
- The implementation of adolescent and women's user committees has had a positive impact on members, organisations and communities, ultimately helping to increase the use of sexual and reproductive health services in the targeted health zones.
- Factors such as the choice of members, the funding structure and the support of community stakeholders, including members of health centres, relatives, schools and traditional leaders, had a considerable influence on the setting up of the committees and the implementation of their activities.

## 1 | INTRODUCTION

An estimated 90% of essential interventions for universal health coverage can be delivered through primary healthcare, notably at the community level.<sup>1</sup> Primary healthcare can be defined as 'a whole-of-society approach to health that aims at ensuring the highest possible level of health and well-being and their equitable distribution by focusing on people's needs and as early as possible along the continuum from health promotion and disease prevention to treatment, rehabilitation and palliative care, and as close as feasible to people's everyday environment'.<sup>1</sup> Strengthening primary healthcare is therefore key to achieve universal health coverage,<sup>2</sup> especially to ensure equitable access to quality health services to geographically, socioculturally and economically disadvantaged populations.<sup>3</sup> Integrated patient-centred or people-centred care is featured prominently in efforts to improve primary healthcare services.<sup>1</sup> Patient engagement is seen as a fundamental strategy for achieving patient-centred care,<sup>4</sup> especially in community-based primary healthcare.<sup>5,6</sup> Yet, its application is still limited in the practices of developing countries, and evidence regarding its implementation modalities and impacts are scarce.<sup>7</sup>

Patient engagement, often referred to interchangeably as patient involvement or participation,<sup>8</sup> can be broadly defined in the case of health care as 'engagement of patients and their family either, in the individual level, in their care and in the decision-making process about their therapeutic plan [or] in contributing to hospital outcomes and objectives as a whole',<sup>9</sup> p. 183. The benefits of involving patients and family members in their care are well documented, leading to a higher-level of satisfaction both patients, families and of healthcare providers.<sup>4</sup> Evidence also suggests that patient engagement has a significant positive impact on patient compliance and self-efficacy, on health outcomes and on the return on investment or cost-effectiveness of care.<sup>10</sup>

Patient engagement can take many shapes depending on the level of implication and the intensity of the expected participation. It can be promoted at the individual care level, at the organisational or clinic level, and at the policy level.<sup>4</sup> Within organisations, patient engagement is said to be driven by a variety of mechanisms, with varying degrees of engagement intensity.<sup>11</sup> Low-level engagement can take the shape of participation through a suggestion box, patient satisfaction interactive terminal or satisfaction surveys, while participation in governance and advisory committees is considered high-level engagement.<sup>5,11,12</sup>

Despite growing interest in patient engagement in Africa, particularly in the Sub-Saharan region, few patient engagement initiatives have been identified, and those are often limited to lower levels of engagement or associated to tokenism representation in governance committees.<sup>13,14</sup> One key underlying factor contributing to this situation is the high prevalence of medical paternalism in healthcare settings, particularly present in African healthcare settings.<sup>15</sup>

Paternalistic approaches to healthcare can be understood as a 'one way relationship between a sick person and an expert physician who manages the sick person and solves their health condition',<sup>16</sup> p. 10. In traditional societies, recourse to medical paternalism is partly explained by cultural factors, such as the lesser importance attached to individual autonomy versus group cohesion and the respect for hierarchical relationships, often due to social status factors intertwined with characteristics such as age, gender and educational background.<sup>15</sup> These cultural factors are coupled with significant differentials in the abilities of patients of developing countries, whose low medical literacy and educational background can cast doubt in providers on their ability to participate in decision-making and to make a relevant contribution.<sup>17</sup> As stated by Norman,<sup>5</sup> p.100 in relation to medical paternalism in Ghana, 'in such a dispossessed environment with stark differential vulnerabilities, physician paternalism is inevitable, informed consent appears overrated and autonomy morphs as an ethical abstraction when it comes to dealing with the seemingly mythical but real 42% of the population being illiterate'.

Even when there is community representation within formal governance or user committees, evidence shows it is influenced by the modalities by which committees were constituted.<sup>18</sup> As a result, higher-level of patient engagement initiatives such as health facility governing committees tend to prioritise elitist representation and can lead to an over-representation of male participants.<sup>18</sup> This poses considerable challenges, as the legitimacy of

patient engagement is intimately linked to the question of representation - and by extension representativeness - of the patients involved.<sup>19,20</sup> Hence the question: how can we foster patient engagement of under-represented or marginalised groups in Sub-Saharan African primary healthcare settings? Using a mixed-method case study design, this paper will try to address this gap by exploring the facilitators and barriers, as well as the results of the implementation of women and adolescents' user committees in Kinshasa, Democratic Republic of Congo (DRC).

## 2 | METHODS

### 2.1 | Case description

With 547 maternal deaths per 100,000 live births, the DRC has one of the highest maternal mortality ratios in Sub-Saharan Africa.<sup>21</sup> Maternal mortality in DRC is heavily influenced by adolescent mortality, particularly because of complications from early and unwanted pregnancies. The high number of unwanted pregnancies, both among teenagers and women, is linked to the limited use and access to quality family planning services, in part due to lack of knowledge about sexual and reproductive health (SRH) and rights, inadequate availability of services, financial, legal and geographical barriers, and to negative provider attitudes (reception, respect for patients' rights, etc.).<sup>22-24</sup> Regarding sexually transmitted diseases (STIs), the HIV prevalence rate remains high with almost 0.63% of women aged 15-49 living with HIV.<sup>21</sup> For both women and adolescents, the difficulty of accessing health services that meet their specific needs is cited as a major barrier to the use of SRH services.<sup>25</sup>

### 2.2 | DRC's health system

The DRC's public health system is designed as a three level 'sanitary pyramid'. The central level encompasses the Ministry of Health, the general secretariat and of health-related national programs. The intermediate level is structured into provinces, then into health districts. The health districts are in turn organised at an operational level into sanitary zones subdivided into sanitary areas, 35 of these comprised in the Kinshasa region.

In an effort to increase access and quality of healthcare services, particularly at the community level, participation mechanisms such as community engagement in the health centres' board of directors, decision-making bodies and health facility management committee were introduced in the last decades. In sanitary areas, small groups of 10 to 15 households elect community relays that can either act as providers of basic health services (minimum package of services), intervene in health promotion or act as community health service volunteers in a specific programme (HIV, etc.). The community relays then elect representatives to the Community Animation Cells, which in turn elect the members of the Health Area Development Committees (CODESA/CODEV) which are responsible for co-managing the health centres and ensuring community participation in the sanitary area.<sup>26</sup> A similar process has been put in place at the communal level (COCODEV), where the CODESA/CODEV presidents elect representatives who will partake in decisions for the health zone. However, these mechanisms do not seem to be achieving the expected results, particularly as the participation and representativeness of certain groups such as women remain low.<sup>24</sup> This is all the more concerning given that women represent the majority of users in SRH services. These issues with representativeness often derive from CODESA/CODEV's constitution modalities and inclusion criteria, such as being a community relay (who are mostly males), having a moderate level of literacy (reading and writing) and being older than 18 years old. As a result, less than a third of the CODESA/CODEV revitalised with the support of the ASSK project were chaired by women (29/92, 31.8%), and adolescent's voices were left out.<sup>27</sup> This lack of representation is all the more problematic given that the lack of access to health services adapted to the needs of women and adolescents has significant repercussions on their use, particularly in the case of SRH services.<sup>28</sup>

## 2.3 | Access to health services in Kinshasa (ASSK) project

The ASSK project is a six year initiative (2018–2024) funded by Canadian Government to increase access and use of quality DSR services of women, adolescent girls and children in seven sanitary zones of the region of Kinshasa, DRC (Bumbu, Kasa-Vubu, Makala, Maluku I, Maluku II, Ngiri-Ngiri and Nsele). With the aim of giving a voice to under-represented community groups in healthcare governance, the project supported the implementation of primary health services user committees. These advocacy user committees were designed to enable the representation of two user groups with specific unmet SRH needs: women and adolescents. In total, four advisory user committees were implemented in three sanitary zones (Makala (WUC), Maluku II (WUC and AUC) and Kasa-Vubu (AUC)), encompassing several health centres. At the time of this study, three groups were still in operation, the latter currently dissolved because of the insecurity in this zone of Kinshasa (AUC Maluku II). This case study focuses on the three user committees still in function.

Using Donabedian's healthcare quality conceptual model (structure, processes and outcomes<sup>29</sup>) to guide our analysis, this study seeks to explore the implementation factors and the results of the introduction of women (WUC) and adolescents (AUC) committees in primary healthcare facilities in Kinshasa, DRC. More specifically, it aims to:

- Explore the WUC and AUC structures, such as its composition and representation, learning and leadership (roles and responsibilities) [Structure];
- Describe the activities planned that were or weren't implemented by the committees [Processes];
- Identify the contributing factors and challenges in user committee's implementation and operations to facilitate the implementation of WUC and AUC in similar contexts [Processes];
- Describe the effects of the implementation of WUC and AUC at the individual (committee members), organisational (primary healthcare facilities) and community levels [Outcomes].

## 2.4 | Data collection

With the aim of enhancing the quality of results through triangulation of approaches,<sup>30</sup> this study employed a mixed-method case study design. The quantitative component of this study utilised secondary data taken from the Ministry of Health's health management information system, the (DHIS2), that's currently used in more than 80 low-to middle-income countries. In DRC, routine data on key health zone indicators are collected at the health facilities in each zone, before being transmitted to the health zone coordinator at the end of the reporting period. The data reported are then entered into the National Health Information System, the DRC's national DHIS2 platform for health information management for each health zones. Data entry and quality control is mostly done in the health zones, with data completion rate routinely exceeding the 80% benchmark.

Qualitative data was collected through two research World Cafés. Regarded as a 'circulating focus group', World Café is an explorative qualitative data collection methodology that gathers multiple stakeholders around a limited number of questions each covering a dimension of a research topic.<sup>31</sup>

As an alternative to traditional group discussions, World Café is seen as a participative and inclusive data collection methodology enabling quality data to be generated from large and heterogeneous groups within a limited timeframe, while addressing the biases associated with power differentials between participants.<sup>32</sup>

Two World Cafés workshops were organised, one for the WUC (July 25th and 26th, 2023) and one for the AUC (26 December 2023). Participants consisted of stakeholders directly involved in the implementation of WUC and AUC, such as members of the user committees, community animators and relays, and representatives of the health centres, of health related and educational programs and of CODESA/CODEVs and COCODEVs representatives (see Table 1 Description of participants per World Café). Themes covered included facilitating factors and obstacles

TABLE 1 Description of participants per World Café (number of participants and profile).

Profile of participant	World Café 1: WUC			World Café 2: AUC		
	Female	Male	Total	Female	Male	Total
User committee members and pairs educators	24	–	24	22	28	50
National adolescent health programme	–	–	–	2	–	2
Ministry of education inspector	–	–	–	–	1	1
Community animators	–	4	4	1	1	2
Community relays	4	2	6	1	3	4
Nurses	2	–	2	2	–	2
Provincial health division and health zone management team	4	7	11	–	–	–
COCODEV and CODESA/CODEV representatives	1	4	5	1	3	4
Total	35	17	52	29	36	65
Facilitators	1	2	3	2	1	3

of user committees' implementation and operations, and perceived impact at the individual, organisational and community levels. After welcoming and introducing the facilitators and workshop objectives and questions, participants were asked to divide into groups of up to 10 people and get seated at the various tables. Each table designated a 'table host' who could write, and who was responsible for documenting on the table's summary sheet the conversations related to each of the questions posed. This was followed by rounds of conversation lasting 20 min, each focusing on a specific question or theme. After each round, participants were asked to change tables (half going to the table on their left, the other half to their right), with only the 'table host' staying still. Before the start of the next round, the 'table host' presented the answers given by the participants to questions and themes already addressed and asked the round of participants if they wanted to add any contributions to what had been presented. At the end of the rounds, an 'harvesting' phase allowed participants to share with the rest of the group the main results for each of the questions and themes and try to collectively identify similarities and trends. For additional information, refer to the COREQ checklist available as a supplemental material appendix.

To ensure validity, workshop questions were draughted by the two experts from Montreal University based on Donabedian's model main themes and validated by the project team members. Furthermore, two of the three workshop facilitators were selected from the project team members with knowledge of the initiative, but without direct participation in the implementation of the user committees assessed, thus limiting potential evaluator and participant biases.

## 2.5 | Data analysis

Quantitative data was analysed through descriptive analysis using the DHIS2 interface. Qualitative data was analysed using Miles, Huberman et Saldana's three-steps thematic analysis: data condensation, presentation, and formulation/validation.<sup>33</sup> Qualitative data were coded manually using inductive coding, and codes were categorised using Donabedian's Structure-Process-Results framework. To increase rigour and trustworthiness, data condensation was completed in two phases. Firstly, a preliminary analysis of the data was first conducted as part of the last phase of each of the World Café (harvest phase—see below). Secondly, the raw material from the World Café (e.g. each table's written summary) was reanalysed by an expert from Montreal University. The results from both analyses were triangulated and then validated with facilitators of the World Café to increase validity through confirmation.

### 3 | RESULTS

The following section highlights the main results of our study according to Donabedian's quality of care model level of analysis: structure, processes, and results.<sup>27</sup>

#### 3.1 | Structure

Each user committee were made up of two structures: an executive committee composed of all committee members, and a six-person management committee elected from the executive committee members. Table 2 (below) highlights the main characteristics of the WUC and AUC committees. The WUC executive committee was made up of women representatives of groups and associations in the sanitary area and who were or have used the SRH services of the associated health centre (see Table 3, below for composition). The management committee was elected from the WUC members, with at least two of them literate either in French or in their native language (reading and writing). Because the members of the executive committee sat as representatives of their organisations or associations, a general assembly, which was open to all associative members, completed the WUC structure. As for AUC, both its committees were made up of an equal number of male and female students between the ages of 15 and 20 who attended the partner schools and had been trained in SRHR or who acted as peer educators. The relationship between user committees and CODESA/CODEVs was also formalised to foster better communication between stakeholders, as the Presidents of CODESA/CODEVs were expected to attend all user committee meetings, and vice-versa.

Based on an assessment of capacity-building needs, committee members were trained in SRHR-related topics (SRH, health rights and patients' rights) and in associative management (management tools, financial management and fundraising). User committee members were then responsible for drawing up their own rules of procedure, which defined the objectives, composition, and powers of the committee; specified the rights and duties of its members; defined the duration and operation (activities) of the committee; and clarified its conflict resolution mechanism, including disciplinary measures and the possibility of sanctions. Both Women and AUC's main aim was patient advocacy, such as raise awareness of SRHR and advocate for better quality SRH services, adapted to their needs, in the partnering healthcare facilities. At the time of their creation, AUC also aimed at supporting the monitoring and evaluation of SRH services for adolescents and youth clientele, by attending the monthly monitoring committee meetings implemented by the partner healthcare facilities. The WUC and AUC management committees met monthly and aimed to be self-sustaining, although their first action plans were funded by the project (see financing, Table 2).

#### 3.2 | Processes

Advocacy user committee processes could be divided into two phases: an implementation (preparatory) phase and an operational phase. The World Café allowed to identify several facilitators and obstacles that have influenced either the user committees' implementation phase, and/or their operational phase (see Table 4 for main themes).

##### 3.2.1 | Implementation phase

Social acceptability having been identified as a major challenge for the initiative, a preliminary community awareness phase was carried out in all three zones. Stakeholders involved included the management team of the sanitary zone (SZ) central office, the head nurse of the health centre and/or the head doctor when the

TABLE 2 Women and adolescent user committees' structure characteristics and composition.

	Women user committee (WUC)		Adolescent user committee (AUC)
Sanitary zone	Makala	Maluku II	Kasa-Vubu
Implementation date	Mar 2021	Mar 2021	Sep 2022
Committee structure	Executive committee		Executive committee
	Management committee		Management committee
	General assembly*		
Admissibility criteria	<ul style="list-style-type: none"><li>• Live in the sanitary zone concerned</li><li>• Be a member of a community animation cell or a community-based organisation</li><li>• Be a woman who uses or has used sexual and reproductive health (SRH) services and respects her appointments at the healthcare centre</li><li>• Be at least 18 years old</li><li>• Agree to be a volunteer</li><li>• Be available for the committee operating activities and implementation of the annual action plan</li></ul> <ul style="list-style-type: none"><li>• Be a student at the school concerned</li><li>• Be a pair educator and/or having been trained/sensitised in sexual and reproductive health and rights (SRHR)</li><li>• Be between 15 and 20 years of age</li><li>• Agree to be a volunteer</li><li>• Be available for committee operating activities and implementation of the annual action plan</li></ul>		
Financing			
Project contribution—action plan implementation	Y1 : 100%	Y1 : 100%	Y1 : 100%
	Y2 : 50%	Y2 : 50%	Y2: N/A

(Continues)



TABLE 2 (Continued)

	Women user committee (WUC)		Adolescent user committee (AUC)
Admission membership fee	3000 CDF	5000 CDF	1000 CDF
	4.90 USD	8.20 USD	1.65 USD
Membership monthly fee (local currency and USD)	1000 CDF	1000 CDF	1000 CDF
	1.65 USD	1.65 USD	1.65 USD

Abbreviations: CDF, Congolese franc; USD, United States Dollar.

TABLE 3 Women and adolescent user committees' structure composition.

	Women user committee		Adolescent user committee
Sanitary zone	Makala	Maluku II	Kasa-Vubu
Composition—Executive committee			
Gender			
Women	100% (n = 26)	100% (n = 27)	50% (n = 14)
Men	–	–	50% (n = 14)
Age			
15–20 years old	15% (n = 4)	19% (n = 5)	100% (n = 28)
21–49 years old	66% (n = 17)	59% (n = 16)	–
50 years old and over	19% (n = 5)	22% (n = 6)	–
Education			
Literate—Lingala	38% (n = 10)	44% (n = 12)	100% (n = 28)
Literate—French	62% (n = 16)	56% (n = 15)	100% (n = 28)
Composition—Management committee			
Gender			
Women	100% (n = 6)	100% (n = 6)	50% (n = 3)
Men	–	–	50% (n = 3)
Gender of the President	Woman	Woman	Man
Age			
15–20 years old	17% (n = 1)	17% (n = 1)	100% (n = 6)
21–49 years old	66% (n = 4)	66% (n = 4)	–
50 years old and over	17% (n = 1)	17% (n = 1)	–
Education			
Literate—Lingala	17% (n = 1)	17% (n = 1)	100% (n = 6)
Literate—French	83% (n = 5)	83% (n = 5)	100% (n = 6)

**TABLE 4** Women and adolescent user committees' main implementation and operational facilitators and obstacles.

	Women user committee	Adolescent user committee
Facilitators		
Implementation phase	<ul style="list-style-type: none"><li>• Pre-existence of women's associations</li><li>• Advocacy with main stakeholders (traditional leaders, and health and education stakeholders)</li></ul>	<ul style="list-style-type: none"><li>• SHR training</li><li>• Associative management training</li><li>• Advocacy with main stakeholders (traditional leaders, and health and education stakeholders)</li><li>• Awareness-raising of AUC among peer-educators</li><li>• Approval of parents and school authorities</li></ul>
Operational phase	<ul style="list-style-type: none"><li>• Members' availability</li><li>• Support and coaching of main stakeholders (community, traditional and religious leaders and healthcare stakeholders)</li></ul>	<ul style="list-style-type: none"><li>• Members' availability</li><li>• Support and coaching of main stakeholders (community, traditional and religious leaders and healthcare and education stakeholders)</li></ul>
Obstacles		
Implementation phase	<ul style="list-style-type: none"><li>• Leadership conflict</li><li>• Lack of confidence of members when speaking</li></ul>	<ul style="list-style-type: none"><li>• Lack of experience in the associative sector</li><li>• Resistance from parents (adolescent SRHR)</li></ul>
Operational phase	<ul style="list-style-type: none"><li>• Logistical challenges (committee management and operations)</li><li>• Financial contribution of members</li><li>• Limited selection of prospective members</li><li>• Resistance from some stakeholders (community and healthcare centres)</li><li>• Context of insecurity</li></ul>	<ul style="list-style-type: none"><li>• Logistical challenges (committee management and operations)</li><li>• Financial contribution of members</li><li>• Limited selection of prospective members</li><li>• Low meeting attendance</li><li>• Resistance from some stakeholders (community, school and inspectors)</li><li>• Context of insecurity</li></ul>

Source: Themes from the World Cafés.

health centre were medicalised, representatives of the provincial health division, the COCODEV and CODESA/ CODEV committees and political, administrative, customary, and religious authorities. User committee focal points were then identified to be involved in all stages of the process and act as reference points for members. Lastly, workshops were conducted with women and adolescents interested in joining the committees to share benefits and best practices in advocacy user committee implementation. Results from the group discussion indicated that these activities have not only raised awareness of the initiative but have also encouraged community support and buy-in, particularly in terms of securing parents and school authorities' consent. Furthermore, they raised awareness of the benefits of advocacy user committees among potential members, such as peer-educators.

More specific to WUCs, the pre-existence of women's associations and the proximity between its members of and the community, as they were themselves users of the health services, were also highlighted as factors facilitating the establishment of user committees.

The community trusts the WUCs being residents of the health areas, they express themselves easily.  
(WUC ID1)

As for AUC, all World Café participants stressed the importance of the training received in the successful implementation of committees, both in relation to SRHR and to committee management.

Although the implementation phase was generally perceived as positive, a number of obstacles were raised. Interestingly, obstacles to setting up user committees differed for women and adolescents user committees. In the case of WUCs, the obstacles raised concerned the members themselves, notably their ability to express themselves in public, and internal conflicts within the groups. While WUC members stressed that being part of a community association was facilitating, many members had great difficulty at first in speaking up and expressing themselves even with this prior experience. Moreover, the fact that the members represented the women's associations from which they came led to conflict in relation to the WUC's governance structure. For example, a member organisation wanted to have a say in the management of one of the WUC, requiring the clarification of the roles and responsibilities of stakeholders around the committee's governance. WUC members also complained of potential conflict of interests arising from the fact that one of the members was both a member of an association and a staff of one of the health centres, hence stressing the need to clarify the membership admissibility criteria. Other membership admissibility criteria were also called into question, such as the member's financial contribution. Despite being seen as a key factor in the sustainability of committees, the member's financial contribution was perceived as a major barrier to participating in activities, especially for adolescents who often lacked personal income.

With regard to the AUC, stakeholders pointed out that teenagers' absence of experience in associative life was an obstacle to the implementation of user committees, particularly in the development of constitutive texts and action plans. In addition, parents' initial misperception of the committees was raised, although this was more associated with the themes addressed than with the idea of the youth association as such. In fact, although parental consent was seen as a facilitating factor for the implementation of AUCs, the taboos surrounding teenager's sexuality remained a barrier not only to the implementation of UAC but also to their operational activities, as described below.

### 3.2.2 | Operational phase

Once the implementation phase was completed and the advisory user committees were formalised, executive committee members were asked to draft an action plan (1–2 years). Operational activities of committees associated with WUC and AUC missions were twofold. On one side, committee members (executive and management,  $n = 117$  in total) were asked to participate in activities to raise awareness on SRH. These included participation in radio programs ( $n = 210$ ) and facilitating community activities ( $n = 40$ ) promoting the use of SRH services available in the healthcare centres. Furthermore, AUC organised two conferences on the theme of risky behaviours among teenagers and young people, attended by close to two hundred teenagers. One of AUC's greatest strengths was its "ease of reaching more adolescents and young people in different parts [of the area]" (AUC, ID3). AUC members not only promoted services, but also accompanied adolescents to health centres, when necessary, thereby increasing adolescents' and young people's access to SRH services. As for WUC, during their awareness-raising and information activities, members collected patient complaints about the SHR services provided by the health centres, which were then forwarded to the CODESA/CODEVs at their monthly meetings, and to the healthcare professionals of the health centres (tri-monthly meeting). If complaints have not been resolved at this level, they were escalated to the authorities at the zone/communal level. Once the corrective actions have been implemented, WUC then monitored community satisfaction with the response to complaints to ensure feedback from beneficiaries.

On the other side, management committee members participated in bi-monthly consultation meetings with key stakeholders, including members of the healthcare facilities, to advocate for improved quality care and access improvement. In addition, AUC members visited health facilities to carry out an audit of the quality and range of services offered to adolescents, including the quality of reception and the cleanliness of facilities. The points for improvement highlighted in the audit report were used to identify the capacity-building needs specific to the facilities, and to guide a range of training courses and workshops (PNSA intervention package, hygiene and

biomedical waste management, family planning, etc.). As for the participation of AUC in the monitoring and evaluation of SDRS services, this objective was not achieved as the health centre monitoring committee was temporarily discontinued due to lack of funding.

In terms of the user committees' operations, facilitators like those previously identified for the implementation phase were mentioned. The availability of members, the dynamism of association leaders and the support of stakeholders from the community, health and educational structures were highlighted as main facilitators of user committees' activities. In addition, the financial and technical support, mainly through the basic training courses, was raised as a factor facilitating the operational activities of the user committees. Several obstacles were nevertheless raised as having hindered the operational activities of the established hay committees. From an operational point of view, the committees' poor logistical resources were raised for both WUCs and AUCs, particularly with regard to the lack of adequate and/or dedicated space for holding meetings and storing documents.

Bad weather, rain and sun prevent the meeting from taking place. [We need] a shed for our protection. [There is] no room to store our equipment.

(WUC ID5)

Despite prior awareness-raising efforts, one of the main obstacles to carrying out the committee's activities was the resistance from certain community stakeholders, particularly from traditional leaders and from members of health and education centres. All participants from both WUCs and AUCs also stressed that the current climate of instability, particularly with regard to inter-ethnic conflicts and street gangs in some parts of Kinshasa, has been a major barrier to carrying out their activities.

Both WUC and AUC members also highlighted that the limited choice of members in view of the eligibility criteria laid down in the by-laws, particularly for the election of officers, was a barrier in the realisation of the committees' activities. Despite understanding the importance of female adolescent's engagement on the committee, some of the AUC participants questioned the need for an equitable gender quota for the various executive positions, believing instead that competence should be the sole criterion for selection. Likewise, the requirement of belonging to an associative group in order to join the WUC was also seen as a barrier to women as individuals who were interested in the activities of the committee but could not join because they were not members of a women's association. Finally, the low participation and attendance of adolescents committee members was identified as a barrier to the implementation of activities for the UAC (62.5% vs. 100% for WUC). According to participants of the AUC World Café, this could be partly explained by the adolescents' limited free time because of their studies and by the discomfort some of them still feel in discussing SRH issues, particularly with their peers.

### 3.3 | Outcomes

Analysis of data collected through the World Cafés and of secondary data drawn from health centre and DHIS2 databases revealed that the implementation of user committees has had a significant impact not only on committee members (individual) and partner health centres (organisational), but also on communities (see main outcomes per level - Table 5 below). The following section presents the main results of the study by level of analysis.

#### 3.3.1 | Individual level (advisory users committee members)

At the individual level, the implementation of user committees seemed to have had a significant impact on the user committee members. Analysis of the two World Cafés highlighted two themes related to the results of

**TABLE 5** Women and adolescent user committees' main outcomes at the individual, organisational and community level.

	Women user committee	Adolescent user committee
Sanitary zone (SZ)	Makala Maluku II	Kasa-Vubu
Individual outcomes—Advisory users committee members		
Individual outcomes—committee members (main themes)	<ul style="list-style-type: none"> <li>• Increase in knowledge and competencies (SRH and health-care system)</li> <li>• Increase in professional skills</li> <li>• Increase in soft skills</li> <li>• Increased empowerment</li> </ul>	<ul style="list-style-type: none"> <li>• Increase in knowledge and competencies (SRH and healthcare system)</li> <li>• Increase in professional skills</li> <li>• Increase in soft skills</li> <li>• Increased empowerment</li> </ul>
Organisational outcomes—Healthcare facilities		
Organisational outcomes (main themes)	<ul style="list-style-type: none"> <li>• Improved access to quality SRH services adapted to women's needs</li> <li>• Increased integration of healthcare services</li> </ul>	<ul style="list-style-type: none"> <li>• Improved access to quality SRH services adapted to adolescent's needs</li> </ul>
Community outcomes		
Perceived community outcomes (main themes)	<ul style="list-style-type: none"> <li>• Healthier SRH (and health) behaviours</li> <li>• Increase in women of the community's engagement in their SHR</li> </ul>	<ul style="list-style-type: none"> <li>• Healthier SRH (and health) behaviours</li> </ul>

Source: World Cafés.

implementing user committees at the individual level, namely: (1) an increase in knowledge and competencies; (2) development of professional skills; (3) development of soft skills, and (4) empowerment of user committee members.

*Increase in knowledge and competencies*

WUC and AUC committee members alike mentioned, among other things, the acquisition of new knowledge, particularly about SRH and available SRH services, and awareness of their SRHR. What's more, the committees were seen as a way for users to speak out and freely express their opinions about their SRHR.

[AUC is] a space for adolescents and young people to express themselves without fear or taboos about sexuality, and to voice their opinions and concerns.

(AUC, ID3)

#### *Development of professional skills*

Participants also mentioned that user committee members had developed professional knowledge and skills, particularly in organisational and financial management, which could be transferred to their professional and personal fields.

On leadership, we've also become family leaders.

(WUC ID1)

#### *Development of soft skills*

Furthermore, members felt that through their participation in the advisory users' committees they have developed their "soft skills" such as their leadership, self-confidence and ability to speak in public and "the courage [...] to speak out." (WUC ID5)

We've developed self-control and self-confidence. We think differently from other young people. What we can do, other young people can't.

(AUC ID4)

AUC members also expressed that they felt better equipped to make good decisions about their sexual health and to pass on information to other adolescents.

The AUC has helped us to take charge of ourselves and to help others to take charge of themselves.

(AUC ID7)

#### *Increased empowerment*

Finally, involvement in users' committees seemed to have empowered members to get involved in other decision-making bodies in their community, whether in the health field (mutual insurance, CODESA/CODEVs, water committee of the general hospital of reference, etc.) or in related community initiatives (managers of Recosites for rapid malaria testing, COVID, etc.).

### 3.3.2 | Organisational level (healthcare facilities)

At the organisational level, advocacy initiatives from the users' committees were generally well received by the authorities and stakeholders in the health zone, although some challenges were observed by the AUCs in health centres where professionals had not been made aware of the initiative.

In terms of confidentiality and needs, [impacts were] much more [observed] in facilities with trained providers. The majority of facilities do not take needs into consideration.

(AUC ID3)

All the participants emphasised the fruitful collaboration between the committees and the CODESA/CODEVs and COCODEVs, which is perceived to have improved access for women and adolescents to quality services tailored to their needs. This perception is supported by the fact that all complaints related to quality or access of SRH services reported to CODESA/CODEV and the healthcare centre authorities by the WUC have been resolved (ASSK 2024).

The feedback loop between beneficiaries and health centres, combined with the user committee's activities, was perceived to have led to many improvements. Analysis of the World Café revealed two themes related to the results of implementing user committees at the organisational level, namely 1) improved access to quality SHR services adapted to women and adolescents' needs, and 2) increased integration of healthcare services.

#### *Improved access to quality SHR services*

Participants emphasised the change in behaviour of health centre providers, particularly with regard to improving reception, respect for patients' rights and confidentiality. The WUC's intervention has also led to the disclosure of fees to combat overbilling, as well as lower fees for certain procedures (childbirth, caesarean section, ovarian cyst surgery, appendicitis). Other improvements have been made to the health centres infrastructure, particularly in terms of sanitation. For example, the mattresses at one of the centres were replaced, as they were worn out, and boreholes were installed to facilitate access to potable water. The lights in the delivery rooms have also been upgraded to better meet patients' needs.

In addition, the WUC's intervention has led to the introduction of SRH services provided by female providers, thus minimising the barrier of customs and traditions against male providers. It has also enabled health centre opening hours to be adapted to meet women's needs, particularly those of a more advanced age, who felt uncomfortable attending SRH consultations with younger women, as well as low-income women, all of whom expressed the need to be seen outside normal opening hours.

[There was] refusal on the part of some women to attend the health centre together with the others for lack of quality clothes. In response, the schedule was changed to favour even the poor.

(WUC ID3)

Similarly, as WUC, AUC members emphasised their impression of bringing about a change in decision-making and in the planning and monitoring of health services adapted to adolescents.

Adolescents are put at the centre of decision-making and health services that concern them. They participate fully in the planning, monitoring and evaluation of health services that concern them.

(AUC ID1)

AUCs members also perceived that the initiative has 'enabled innovation in adolescent health services'. (AUC ID4) However, participants highlighted that there are still several challenges to be overcome, as 'SRH care is not provided effectively and [issues subsist] such as consultation, out-of-pocket expenses, reception and confidentiality.' (AUC ID2).

#### *Increased integration of healthcare services*

Furthermore, WUCs have enabled better integration of pre and post-natal consultations, childbirth, family planning and vaccination services. Finally, to ensure comprehensive SRH services while limiting patient transfers, a request was made to provide one of the health centres with an ultrasound machine.

3.3.3 | Community level

Lastly, the implementation of user committees is perceived by participants to have had a significant impact at the community level. Analysis of the World Cafés has highlighted two themes related to the results of implementing user committees at the community level, namely: 1) healthier SRH behaviours, and 2) increase of women engagement in their SHR.

*Healthier SHRH behaviours*

The implementation of advocacy user committees seems to have fostered awareness and the adoption of better health habits and behaviours by community members, not only in terms of community members adopting healthy SRH behaviours such as modern family planning, but also in terms of the reduction of risky behaviours such as drug and alcohol use.

[Before] it was difficult to accept planning in Mbankana because of rumours in the community about the effects of implants on the body

(WUC ID2).

This seems to have led to an increase in the number of patients seeking care at our health centres, as “the health centre was 30% occupied, now it's 80% [occupied]” (WUC ID1). These perceptions seem to be corroborated by DHIS2 data, which show a marked increase in family planning consultations and assisted deliveries among women aged 15–49 in user committee intervention zones (see Table 6, below).

These significant impacts were also observed in adolescents and youth of the community that were not involved in the UAC.

The subject of teenagers' sexual and reproductive health was taboo. Ignorance is removed in relation to sexual and reproductive health. [...] Now teenagers are aware of their sexual and reproductive health problems, and we're working to raise their awareness and change their behaviours, learning how to wear condoms correctly, how to calculate their menstrual cycle and how girls use [contra-ceptive] pills [and] reducing the use of psychoactive substances among adolescents and young people.

(AUC, ID2).

TABLE 6 Main outcome indicators relating to SHR per sanitary zone, 2022–2024.

	Makala	Maluku II
Percentage of women and adolescent girls that use SRH services (yearly)	73.6%	56%
	Baseline: 12%	Baseline: 35%
	613% increase	160% increase
Percentage of women and adolescents that have an assisted delivery	32%	56%
	Baseline: 10%	Baseline: 50%
	320% increase	12% increase
Percentage of women and adolescents using family planning services	8.5%	16%
	Baseline: 3%	Baseline: 13%
	283% increase	23% increase

Source: DHIS2.



This strategy seems to have paid off. Overall, an 19% increase in new family-planning services users in adolescents was observed in the period under review.

AUC has given us access to sexual and reproductive health services. Before, there was limited knowledge.

(AUC, ID6)

Apart from HC Sainte-Marie, the number of new teenagers accepting contraceptive methods has almost doubled among the partnering health centres. Furthermore, a 34,5% reduction in STI-related new consultations of adolescents 15–24 years of age was observed in the Kaza-Vubu SZ. It should be noted, however, that this impact is most likely attributable to the combination of the AUC's SRH awareness-raising activities and the free STI treatment campaign carried out the previous year by the project.

#### *Increase in women of the community's engagement in their SHR*

Ultimately, the implementation of advisory user committees seems to have led to an increase in women and adolescents' engagement in their SDSR. As stated by one of the participants:

The WUCs are a success factor for women's joint participation, as women are the pillars of the community, and it's through them that we can have everyone's assent. [...] With the WUC, women were able to say out loud what they had been saying in silence. With WUC, the search for equity became effective.

(WUC ID2)

## 4 | DISCUSSION

This study aimed to explore advocacy user committees of under-represented or marginalised groups such as adolescents and women in their ability to foster greater patient engagement, and by extent increasing access to quality care adapted to their needs, in a Sub-Saharan context. Our results highlighted that the implementation of WUC and AUC in DRC has had significant impacts at the individual, organisational and community level. At the individual level, implementation of user committees was identified with an increase of SRH knowledge and competencies, of professional knowledge and soft skills and of empowerment of the user committee members. In addition, at the organisational level, WUCs and AUCs seem to have improved access to quality care adapted to patients' need, and of certain modalities of SRH services. Finally, at the community level, they were associated with an increase of the SRH literacy and of patient engagement of women and adolescents of their community. These findings corroborate those of Haddad et al.<sup>34</sup> who estimated that 15 additional assisted deliveries could be attributed to the presence of WUCs in the three zones of the project in Burkina Faso and Mali. They also support other studies' conclusions in Sub-Saharan contexts that found that community and patient engagement positively influence use of healthcare services and health outcomes.<sup>6,35,36</sup>

Our study also questioned the ability of user committees to empower patient engagement in the individual care level in contexts where medical paternalism is prominent. Overall, our results seem to indicate that the implementation of advocacy user committees have led to greater patient engagement at the episode of care level, as illustrated by an increased ease of women and adolescent patients to express their SRH needs and opinions regarding services offered. Yet the extent of this engagement in the context of care episodes with the providers themselves (i.e informed consent, participation in care, patient autonomy, etc.) and its effects needs to be further explored.

Several facilitating factors and obstacles that will need to be considered when setting up user committees in similar contexts in the future were also identified. The fact that WUC members were already involved in associations and organisations was raised as a facilitating factor, echoing prior WUC implementation initiatives in Haiti, Burkina Faso and Mali, where the importance of existing leadership among members was also noted.<sup>37,38</sup> In line with Ankhoma and al.,<sup>14</sup> our study also highlights the importance of community healthcare workers support and collaboration, that were perceived critical to effective patient engagement initiatives success such as in user committee's implementation and operations. Our results furthermore reinforce the necessity of taking into account the important influence of key traditional and religious stakeholders and involving them not only in the preparatory phases but also in the activities of advocacy user committees in Sub-Saharan contexts.

Ultimately, this study also raises the question of representation and representativeness. As advocacy users' committees, the aim of WUC and AUC was to act as transmission belts and spokespersons for women and adolescents vis-à-vis the health centres and health system stakeholders. Hence the committee's membership inclusion criteria requiring current or previous use of services and a minimum level of knowledge of SRH. In addition, to make medical documentation easier to understand, the WUC required a proportion of its executive members to be able to read and write in French. This need for basic literacy (general or medical) is believed to be one of the main factors facilitating the setting up and operation of committees, in line with the findings cited in the literature.<sup>35</sup> However, this raises a concern about potential representativeness bias between the composition of the committees and that of the populations in the DRC's health zones, where one out of five men and two out of five women aged 15–49 years cannot read a short simple statement.<sup>39</sup> This representativeness bias is all the more prevalent among teenagers whose members had to attend school to be able to join the AUC, considering the low rates of school attendance in DRC (in 2007, youth school attendance rates was 27% of 12–17 years old for all of the DRC, but as low as 56% for Kinshasa). These concerns about the limitations of direct patient engagement methods such as user committees in regard to representativeness have also been raised by Crawford and Rutter,<sup>40</sup> and Sandman et al., the latter going as far as to state that 'in practice, patient representation in [the basis of deliberative democracy] is likely to be impossible, and any attempt to implement it risks being biased towards some stakeholders at the expense of others',<sup>41</sup> p. 409. However, we agree with Scolz et al. that 'representation itself is not the end goal but is rather a means to ensuring decision-making and agenda-setting in health systems is held more equitably',<sup>42</sup> p. 8.

## 4.1 | Limitations

Despite efforts to ensure the validity of the results, notably through data triangulation, certain limitations remain. One limitation is the short time elapsed between implementation of the committees and evaluation of their impact. This raises questions about the sustainability of its effects, especially once funding for the pilot project is no longer available. Regarding secondary data, potential biases include the variable quality of data related to SRH services rendered, the limited number of health data collected, and the lack of age-disaggregated data for the health centres' outcome indicators. Furthermore, concerns about potential response bias were raised about the fact that facilitators were part of ASSK project team even though most were not directly involved in the committees' activities. However, the data and methodological triangulation, introduced to limit biases, reinforces our confidence in the validity of our findings.<sup>43</sup>

## 4.2 | Conclusion

This paper aimed to address the considerable gap in the literature regarding patient engagement initiatives in primary healthcare services in Sub-Saharan Africa. Using results from a mixed-method case study, it explored the structure, processes, and outcomes of three advocacy user committees involving under-represented groups in

healthcare services: adolescents and women. Furthermore, this paper discussed facilitating factors and obstacles to the implementation and activities of user committees in the DRC context that could be useful for future implementations. Still, further studies are needed to better understand the multilevel impact of setting up advocacy user committees in Sub-Saharan Africa, and to ensure that they remain in place once pilot project funding has been completed.

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## ETHICS STATEMENT

This assessment was an activity part of a Government of Canada's funded initiative. Ethical approval was not mandatory but the assessment had to follow *the Government of Canada's ethical guidelines*.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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