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# BMJ Open

## Experiences and resultant care gaps among women with HIV in Canada: Concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) Findings

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3 Experiences and resultant care gaps among women with HIV in Canada: Concept  
4 mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study  
5 (CHIWOS) Findings  
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7  
8 **Abstract**  
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10 **Objectives:** The community-based, longitudinal, Canadian HIV Women's Sexual and  
11 Reproductive Health Cohort Study (CHIWOS), explored the experiences of women  
12 living with HIV in Canada over the past decade. CHIWOS' high impact publications  
13 document significant gaps in the provision of health care to women living with HIV. We  
14 used concept mapping to analyse and present a summary of CHIWOS findings on  
15 women's experiences navigating these gaps.  
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23 **Design:** Concept mapping procedures were performed in two steps. First, two reviewers  
24 (AY and PM) independently reviewed CHIWOS manuscripts and conference abstracts  
25 written before 1 August 2019 to identify main themes and generate individual concept  
26 maps. Next, the preliminary results were presented to national experts, including women  
27 living with HIV, to consolidate findings into an overall visual summarizing the  
28 experiences and care gaps of women living with HIV in CHIWOS.  
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37 **Setting:** British Columbia, Ontario and Quebec, Canada.  
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40 **Participants:** Healthcare professionals who care for people living with HIV, researchers,  
41 and cis-gender and transgender women living with HIV.  
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44 **Results:** Overall, a total of 59 peer-reviewed articles and conference abstracts met the  
45 inclusion criteria. Using concept mapping, themes were generated and structured through  
46 online meetings. In total, six concept maps were co-developed: quality of life, HIV care,  
47 psychosocial and mental health, sexual health, reproductive health, and trans women's  
48 health. Two summary diagrams were created, one for all women and one specific to trans  
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3 women. Resilience, social support, positive healthy actions, and women-centred HIV care  
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5 were highlighted as strengths leading to well-being for women with HIV.  
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8 **Conclusions:** Concept mapping resulted in a composite summary of 59 peer-reviewed  
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10 CHIWOS papers. This activity will allow for priority setting of positive actions for  
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12 optimizing care and well-being for women with HIV.  
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17 **Keywords:** HIV, women's health, healthcare systems, care gaps, concept mapping  
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### Strengths and limitations of this study (Article Summary)

- The study comprehensively summarizes the health experiences of women with HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) and identifies potential gaps in their care.
- A diverse group of women living with HIV experts across Canada took part in this study to provide feedback on the concept maps which used results from 59 peer-reviewed publications by, with and for women living with HIV.
- The process of concept mapping and reviewing visualizations with key informants occurred from June 2019 to March 2021, hence no later data could be included in the summarization of key CHIWOS publication findings.
- This is the first study to explore a composite of the findings from CHIWOS manuscripts and conference abstracts using the methodology of collaborative concept mapping.

### Background

Recent studies have found that women living with HIV experience unique health and social needs that differ from those of men living with HIV and limit their access to treatment and care services.<sup>1-3</sup> The historical lack of research focusing on the realities of women living with HIV is potentially detrimental to the health of women.<sup>4,5</sup> These circumstances led to the development and implementation of the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) – the largest community-based study in Canada exploring the experiences and priorities of a diverse,

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2  
3 national cohort of women living with HIV in British Columbia (BC), Ontario (ON), and  
4  
5 Quebec (QC) from 2011-2021.  
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8 CHIWOS was initiated in 2011 through a qualitative phase, which informed the  
9  
10 creation of an in-depth survey.<sup>1,2</sup> The study's objectives were to examine women's access  
11  
12 to women-centred HIV care and the impact of corresponding patterns of use on health  
13  
14 outcomes.<sup>2</sup> CHIWOS was guided by principles of equitable involvement of those affected  
15  
16 *by the research in the research process* by establishing community-academic partnerships  
17  
18 and shared decision-making throughout the study.<sup>6,7</sup> This research approach, reflecting  
19  
20 community-based research (CBR) approaches, was enacted in part through the  
21  
22 involvement of women living with HIV as trained community researchers in each stage  
23  
24 of the research.<sup>2,8,9</sup> CHIWOS was created by, with, and for women living with HIV in  
25  
26 collaboration with academic researchers, clinicians, and community partners to  
27  
28 investigate women's mental, sexual and reproductive health care priorities, and need for a  
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30 women-centred HIV care model.<sup>1,2,10</sup> Cohort data collection was launched in 2013 in  
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32 three Canadian provinces (BC, ON, QC). Survey data were collected at three-time  
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34 points, 18 months apart, from August 2013 to September 2018. A complete description of  
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36 CHIWOS can be found at [www.chiwos.ca](http://www.chiwos.ca). CHIWOS remains the largest longitudinal  
37  
38 study of women with HIV in Canada, successfully enrolling a diverse cohort of 1,422  
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40 women with HIV (356 from BC [25%], 713 from ON [50%], and 353 from QC [25%]).<sup>1,2</sup>  
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47 As of August 2019, our team, including women living with HIV, produced 116  
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49 publications (53 articles and 60 conference abstracts) using CHIWOS data. This  
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51 academic content explores dozens of specific topics related to the experiences of women  
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53 living with HIV, including psychosocial determinants, clinical, mental, sexual,  
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3 reproductive health outcomes, access to, and quality of healthcare that characterize  
4 women's health gaps and needs and that can be used to inform programming and policy  
5 in Canada. In an effort to better understand the main topics and gaps of CHIWOS  
6 manuscripts and conference abstracts, this study applied a form of concept mapping used  
7 in education, as according to Novak and Gowin (1984).<sup>11</sup> The goal of this methodology  
8 was to visualize concepts of CHIWOS findings in a hierarchical fashion, with the most  
9 inclusive and general concepts at the top of the map, and specific concepts arranged  
10 hierarchically below to represent the inter-related relationships in each publication  
11 included. We sought to apply these findings towards the creation of a summary diagram  
12 to summarize the health experiences and gaps of women living with HIV enrolled in  
13 CHIWOS. An added benefit of using concept mapping in this study is that the simplistic  
14 visualizations allow for increased accessibility of the CHIWOS findings to those outside  
15 of academia, including community members and knowledge users. Our goal was to use  
16 these findings to characterize women living with HIV's healthcare needs and gaps to  
17 inform policy and programming in Canada.

## 37 **Methods**

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40 Concept mapping is a graphical methodology used to organize and present  
41 knowledge. Since its conception by Novak (1974)<sup>12</sup>, it has been adapted in education as a  
42 learning tool to capture expert knowledge and in qualitative research to present findings  
43 and analyse themes.<sup>13,14</sup> This methodology was chosen to illustrate the key themes from  
44 the CHIWOS publications, including both manuscripts and conference abstracts, and  
45 their relation to each other in order to demonstrate the experiences and related gaps in  
46 care women living with HIV face in Canada. Understanding the intersectional complexity  
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3 of the data, a social-ecological perspective was applied to further understand the interplay  
4  
5 between multi-level factors of women living with HIV, their community, and society.<sup>15-17</sup>  
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8 For this study, the concept mapping process from Novak (1998)<sup>18</sup> was used to  
9  
10 encompass five steps:

11  
12 **Step 1:** Conduct a thematic analysis on CHIWOS publications and summarize key  
13  
14 findings  
15

16 All CHIWOS publications (including manuscripts and conference abstracts)  
17  
18 published, under review, or near publication submission before 1 August 2019 were  
19  
20 examined alongside inclusion criteria developed by the core concept team (including AY,  
21  
22 MK, ML, and PM). To be included for review, publications were to 1) include national  
23  
24 quantitative CHIWOS questionnaire data, and/or 2) be published, under review or near  
25  
26 submission in a peer-reviewed journal. Publications that included qualitative CHIWOS  
27  
28 data, utilized only provincial data, were process or methods pieces, or were in-press were  
29  
30 excluded. Figure 1 shows the selection process. A total of 116 CHIWOS publications  
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32 (including articles and conference abstracts) were reviewed of which 57 were excluded.  
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34 This resulted in 59 eligible publications that met the inclusion criteria (summarized in  
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36 Table 1). Eligible publications were grouped together by theme and discussed further in  
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38 step 3.  
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44 **[insert Figure 1 here]**  
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**Table 1:** Summary of Included CHIWOS Publications

Concept Map Theme	Manuscript Citation (n=44)	Abstract Citation (n=15)
Quality of life	n=4 <a href="#">Logie, Wang et al. 2018</a> <a href="#">Carter, Loutfy et al. 2018</a> <a href="#">Kteily-Hawa, Andany et al. 2019</a> <a href="#">Kteily-Hawa, Warren et al. 2019</a>	
HIV care	n=8 <a href="#">Kennedy, Mellor et al. 2020</a> <a href="#">Kerkerian, Kestler et al. 2018</a> <a href="#">Kronfli, Lacombe-Duncan et al. 2017</a> <a href="#">Kronfli, Lacombe-Duncan et al. 2017</a> <a href="#">Logie, Wang et al. 2018</a> <a href="#">Loutfy, de Pokomandy et al. 2017</a> <a href="#">O'Brien, Godard-Sebillotte et al. 2019</a> <a href="#">Shokoohi, Bauer et al. 2019</a>	n=4 Conway, Gormley et al. 2019 Kaida, Conway et al. 2019 Loutfy, de Pokomandy et al. 2015 Puskas, Pick et al. 2018
Psychosocial & mental health	n=14 <a href="#">Carter, Roth et al. 2018</a> <a href="#">Churchill. 2018</a> <a href="#">Gormley, Nicholson al. 2021</a> <a href="#">Heer, Kaida et al. 2022</a> <a href="#">Jaworsky, Logie et al. 2018</a> <a href="#">Logie, Lacombe-Duncan et al. 2018</a> <a href="#">Logie, Marcus et al. 2019</a> <a href="#">Logie, Wang et al. 2018</a> <a href="#">Logie, Williams et al. 2019</a> <a href="#">Patterson, Nicholson et al. 2020</a> <a href="#">Shokoohi, Bauer et al. 2018</a> <a href="#">Shokoohi, Bauer, Kaida et al. 2019</a> <a href="#">Shokoohi, Bauer et al. 2019</a> <a href="#">Wagner, Jaworsky et al. 2018</a>	n=4 Kaida, Nicholson et al. 2019 Logie, Wang et al. 2019 Parry, Lee et al. 2019 Underhill, Wu et al. 2018
Sexual health	n=8 <a href="#">Carter, Greene et al. 2018</a> <a href="#">Carter, Greene, Money et al. 2018</a> <a href="#">Carter, Greene et al. 2019</a> <a href="#">Carter, Patterson et al. 2020</a> <a href="#">de Pokomandy, Burchell et al. 2019</a> <a href="#">Kaida, Carter et al. 2015</a>	n=2 Salters, Loutfy et al. 2015 Underhill, Kennedy et al. 2017

	<a href="#">Logie, Kaida et al. 2020</a> <a href="#">Patterson, Carter et al. 2017</a>	
Reproductive health	n=6	n=4
	<a href="#">Andany, Kaida et al. 2020</a> <a href="#">Fortin-Hughes, Proulx-Boucher et al. 2019</a> <a href="#">Kaida, Patterson et al. 2017</a> <a href="#">Salters, Loutfy et al. 2017</a> <a href="#">Skeritt L, de Pokomandy et al. 2021</a> <a href="#">Valiaveetil, Loutfy et al. 2019</a>	Boucoiran, Kaida et al. 2019 Kaida, Gormley et al. 2019 Kaida, Money et al. 2017 Siou, Salters et al. 2016
Trans women living with HIV	n=4	n=1
	<a href="#">Lacombe-Duncan, Bauer et al. 2019</a> <a href="#">Lacombe-Duncan, Newman et al. 2017</a> <a href="#">Lacombe-Duncan, Warren et al. 2021</a> <a href="#">Logie, Lacombe-Duncan et al. 2018</a>	Lacombe-Duncan, Persad et al. 2017

See Supplementary 1 for included publications citations.

From the 59 included manuscripts and conference abstracts, we began by identifying the major findings of each that answered the guiding question: what are the experiences among women living with HIV who participated in CHIWOS regarding their psychosocial determinants, clinical, mental, sexual and reproductive health outcomes and access to and quality of healthcare that characterize their healthcare gaps and needs and that can be used to inform policy and programming in Canada? We then used the coding step of a thematic analysis<sup>19</sup> to code the findings into their simplest form (e.g., lower food security is associated with increased substance use). As a last step, we listed the concepts and linking words within each code (e.g., concepts = lower food security, substance use; linking words = is associated with).<sup>19</sup> This process was repeated for each manuscript and conference abstract.

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3 **Step 2: Individual concept mapping of CHIWOS manuscripts and abstracts**  
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5           The concepts and linking words from Step 1 were used to guide the design of 59  
6 individual concept maps, each visually summarizing the key findings of one manuscript  
7 or conference abstract. Figure 2 is an example of one of the individual concepts we  
8 created from the CHIWOS findings.  
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14 **[insert Figure 2 here]**  
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18           Within each map, concepts were listed in hierarchical order with the most  
19 overarching general concepts at the top and the most specific concepts at the bottom.<sup>11</sup>  
20 Using an online software, CMAPTools<sup>20</sup>, concepts were designated by boxes and lines  
21 were drawn from one concept to another with the linking words placed in between. An  
22 arrowhead guided the direction of the relationship between the two concepts. We adapted  
23 the concept map process by adding in extra features that better visually represent the  
24 CHIWOS findings. For example, arrowheads pointed towards outcomes of CHIWOS  
25 findings. Bi-directional arrows were used when a relationship was present between two  
26 outcomes. Solid lines represented a positive association between concepts while dotted  
27 lines represented a negative association between concepts. Concepts that recurred in two  
28 or more individual concept maps were considered critical findings and were designated  
29 by a blue shaded concept box.  
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45           AY and PM independently reviewed each concept map to ensure all major  
46 findings were represented and summarized into the visual. If there was a discrepancy, a  
47 third reviewer (ML) was consulted to make the final decision.  
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3 **Step 3:** Compilation of individual concept maps into composite concept maps  
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5 AY, PM, and ML grouped the maps with main concepts with similar themes together. Six  
6 major themes were identified: quality of life, HIV care, psychosocial and mental health,  
7 sexual health, reproductive health, and trans women living with HIV.  
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10 The individual concept maps that fell under each major theme were compiled  
11 together to create a composite concept map. AY and PM drew cross-links between  
12 concepts that had relationships but were on different domains of the composite concept  
13 map.<sup>14</sup> This process was repeated for each theme and six composite concept maps were  
14 developed.  
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17 **Step 4:** Internal development team review and brainstorming of overarching visualization  
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20 An internal team (including AY, MK, ML, and PM) meeting was held in August  
21 2019 to review all six composite concept maps. The goal was to ensure all key findings  
22 were represented on the maps with good readability. The guiding question was referred to  
23 when deciding to remove or add concepts to the map.  
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26 The team was asked to brainstorm ideas to design a compilation visual  
27 representing the findings of the six composite maps that answered our guiding research  
28 question. A preliminary sketch was formed which is now referred to as the summary  
29 diagram.  
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32 **Step 5:** External expert team review and validation  
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35 The first author of each included CHIWOS manuscript and conference abstract  
36 (herein referred to as lead investigators), and all CHIWOS community researchers were  
37 identified as potential key participants in this study and were approached for recruitment  
38 from October 2019 to November 2020. A total of six CHIWOS lead investigators  
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3 representing different disciplines, and 26 community researchers from each of the three  
4 provinces were invited to participate in the study by email. A total of 29 meetings were  
5 held with groups of participants and took place both in-person and virtually.  
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10 For orientation, introductory slides explaining the concept mapping methodology  
11 and its application to CHIWOS findings were shown to the group. Each of the six  
12 composite concept maps were then presented. Lead investigators were asked to ensure  
13 that all major CHIWOS findings were accurate and present, and community researchers  
14 were asked to ensure that the experiences of women living with HIV were accurately  
15 represented. All participants were asked to provide input on the readability, clarity, and  
16 inclusivity of language. Next, the summary diagram was presented and participants were  
17 asked to ensure that all key components from the composite concept maps were included  
18 in the summary diagram, in addition to providing feedback on design features including  
19 colour, layout, and display of content. All participant feedback was documented and the  
20 feedback between different focus groups were compared. All suggestions and changes  
21 were reviewed by AY and PM through revisiting the manuscript and abstracts and  
22 addressing the guiding research question. Updated composite theme maps and the  
23 summary diagrams were presented at a follow-up meeting and consensus was reached by  
24 discussion.  
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44 The study was assessed to not require ethical approval by a human research ethics  
45 committee by the research team because the Ethical Principles for Medical Research  
46 Involving Human Subjects did not apply. Instead, participants, all of whom had been  
47 previously engaged as CHIWOS team members, were recruited on a volunteer basis. We  
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3 obtained informed consent from all participants. Community partners were compensated  
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5 for their involvement in this project.  
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## 7 8 **Results**

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10 A total of 18 individuals participated in this study including six lead investigators  
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12 (BC: n=1; ON: n=3; QC: n=2), and 12 community researchers (BC: n=5; ON: n=7). All  
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14 participants identified as women (cis-gender and transgender). There was diverse  
15  
16 representation across age, race, ethnicity, and gender identity demographic categories.  
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### 19 **Composite Concept Maps**

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21 Overall, six composite maps were created (see Supplemental Figures 1-6).  
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24 We developed composite map 1 (see Supplemental Figure 1) from four  
25  
26 manuscripts focused on the topic of quality of life. Notable findings in this concept map  
27  
28 include bi-directional association of physical and mental health quality of life, and the  
29  
30 association of experiences of women-centred HIV care with higher resilience and in turn  
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32 higher quality of life. This map illustrates the influence socioeconomic status,  
33  
34 experiences of stigma, sexual orientation, substance use, social support, and relationship  
35  
36 status have on mental and physical health-related quality of life.  
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40 From eight manuscripts and four conference abstracts, map 2 (see Supplemental  
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42 Figure 2) was created to illustrate findings related to HIV care. This map demonstrates  
43  
44 associations between several aspects of HIV care including viral suppression, use of  
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46 combination antiretroviral therapy (cART), care access and attrition. Notable findings  
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48 include the effect social and peer support have on increasing access to HIV care and the  
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50 effect of racial discrimination on care attrition. Violence in adulthood was found to  
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52 reduce cART use and adherence, leading to reduced viral suppression. On the other hand,  
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3 peer leadership involvement was associated with higher awareness of cART prevention  
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5 benefits.  
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8 Map 3 (see Supplemental Figure 3) demonstrates the connections between various  
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10 facets of psychosocial and mental health and represents data from 14 manuscripts and  
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12 four abstracts. Indigenous heritage was associated with higher violence in adulthood as  
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14 well as lower housing security and income. Food security was associated with higher  
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16 substance use. This map emphasizes the impact of intersectional stigma on all aspects of  
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18 mental health, which are associated with clinical measures like cART initiation.  
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21 The most complex of the six visuals is map 4 (see Supplemental Figure 4) which  
22  
23 explores sexual health experiences of women enrolled in CHIWOS. This map represented  
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25 data from eight manuscripts and two abstracts. Its findings were organized into social and  
26  
27 medical aspects of sexual health sub-categories. A main finding was the association of  
28  
29 higher depression and violence in adulthood with lower pleasure and satisfaction in  
30  
31 relationships. Higher HIV-related stigma was also associated with higher sexual  
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33 inactivity in the past six months, which was a recurring theme to emerge in the included  
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35 publications.  
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40 The fifth map (see Supplemental Figure 5) showed CHIWOS findings related to  
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42 reproductive health. The production of this map as separate from sexual health was  
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44 intentional to illustrate that for many women, sexual health goes beyond reproductive  
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46 health desires or lack thereof. This map drew on data from six manuscripts and four  
47  
48 abstracts, and includes sub-categories of menstruation, pregnancy, contraceptive use, and  
49  
50 early menopause. Findings showed low use of a narrow range of contraceptive methods,  
51  
52 with sexual orientation, previous pregnancies, and age influencing contraceptive choice.  
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3 Service provider counselling on choices for feeding practices, infant feeding support and  
4 free formula programs were associated with positive infant feeding experiences for  
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6 women.  
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10 The final map titled trans women concept map (see Supplemental Figure 6)  
11 included topics from all five of the other concept maps from the exclusive perspective of  
12 trans women in CHIWOS, with data drawn from four manuscripts and one abstract that  
13 solely analyzed trans women's data. This map shows trans women's experiences of  
14 gender discrimination and transphobia, which influence barriers to gender affirming and  
15 general HIV care, with HIV-related stigma playing a significant role in this association.  
16  
17 Higher sexual relationship power was associated with lower depression/PTSD symptoms.  
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19 Higher social support was associated with resilience, which trans women experienced  
20 higher levels of than cis women in CHIWOS.  
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### 30 **Summary Diagrams**

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32  
33 Community partners engaged in arts-based design of the two summary diagrams.  
34 It was important to the community partners that the visuals were rooted in the stories and  
35 experiences of CHIWOS participants, and its elements were accessible, empowering,  
36 holistic, authentic, and inclusive. These were the words community partners used in our  
37 meetings together while co-developing the figures.  
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44 From the six composite concept maps, two summary diagrams were created (see  
45 Figures 3 and 4), one for all women and one for trans women in collaboration with the  
46 three CHIWOS lead investigators and 26 community researchers who participated in the  
47 study. A total of 29 meetings were held to create these visuals. These diagrams provide a  
48 summary of the key insights, barriers, and supports that affect the health and well-being  
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3 of women living with HIV involved in CHIWOS. From the 59 publications and six  
4  
5 composite concept maps, it was found that a socio-ecologic model was appropriate to  
6  
7 show how individual, societal, and structural factors affect women's health and well-  
8  
9 being.<sup>11-13</sup> As a result, the diagram was created in the shape of concentric circles. At the  
10  
11 centre of both visuals is a speaking bubble highlighting the stories that women who  
12  
13 participated in CHIWOS shared and was named by the team's Indigenous Elder (VN):  
14  
15 "Honouring Their Voices." The inner circle of both figures highlights the aspects that are  
16  
17 important to women's quality of life: HIV health, general health including physical,  
18  
19 health, sexual and reproductive health, mental health, violence and trauma, substance use,  
20  
21 culture and spirituality, and resilience. Surrounding quality of life are social factors that  
22  
23 combine to affect the health of individuals and their communities, such as housing  
24  
25 stability, food security, income, and social isolation. The outer circle consists of the  
26  
27 structural factors that affect health including HIV-related stigma, and gender and racial  
28  
29 discrimination. Intersecting these layers of the women's health experiences are the  
30  
31 important ways women are addressing barriers in their lives, including social support,  
32  
33 accessing, or calling to action the need for women-centred HIV care (WCHC), and  
34  
35 positive healthy actions.  
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42 **[insert Figure 3 here]**  
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44  
45 Through consultations with trans women on the composite maps, the second  
46  
47 summary diagram (see Figure 4) was created to reflect the most important and recurring  
48  
49 findings of the concept mapping exercise as they relate to the experiences of trans women  
50  
51 with HIV involved in CHIWOS. The main difference from Figure 3 is the addition of  
52  
53 gender affirmation in the inner circle in reference to trans women's experiences.  
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3 Community researchers define gender affirmation whereby an individual receives the  
4 affirmation they desire from those around them, including social recognition and/or  
5  
6 medical access to hormone therapy and gender-affirming surgeries.  
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10 **[insert Figure 4 here]**  
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12 These figures show that there are both commonalities and differences in the  
13 experiences of women living with HIV; however, resilience was present among all  
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19 With meeting facilitation support from The Public Studio, an activist design  
20 studio in Toronto (<https://thepublicstudio.ca/>), we identified that community partners  
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## 33 **Discussion**

35 The six composite concept maps and two summary diagrams encapsulate the  
36 work conducted by the CHIWOS team over the past decade. They culminated into a  
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47 A recurring theme in the concept maps and summary diagrams was the lack of  
48 receipt of comprehensive WCHC,<sup>28</sup> including lack of discussion of reproductive goals,  
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3 with HIV such as the Canadian HIV Pregnancy Planning Guidelines, the Guidelines for  
4 the Use of Antiretroviral Agents in Adults and Adolescents with HIV, and the British  
5 Columbia Guidelines for the Care of HIV Positive Pregnant Women & Interventions to  
6 Reduce Perinatal Transmission, and trans women living with HIV like the Sherbourne's  
7 Guidelines for Gender-Affirming Primary Care.<sup>21-23,30</sup> The concept maps also  
8 demonstrate the negative effects of low socioeconomic status and stigma and  
9 discrimination on women's self-reported resilience. This could impact the ability to self-  
10 advocate in healthcare settings, further affecting quality of care received. This finding has  
11 important implications to how clinicians and service providers approach care  
12 relationships and the importance of practicing from a person-centred lens.  
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26 The creation of separate concept maps for cis and trans women shows the  
27 important similarities and differences between cis and trans women's experiences. Our  
28 findings show many similarities in the health experiences of cis and trans women living  
29 with HIV in CHIWOS were shared.<sup>25</sup> This is important for providers who often assume  
30 providing care to trans women living with HIV requires a unique skillset and approach.<sup>26</sup>  
31 The key differences in the summary diagrams were gender affirmation at the individual  
32 level, as well as trans care knowledge and training at the structural level. Obtaining  
33 training in trans health and gender affirmation is a manageable goal that providers can  
34 achieve to deliver more competent care to trans women living with HIV.<sup>27</sup>  
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47 A main strength of this study is the richness of CHIWOS dataset analyses  
48 conducted over the last 10 years. This study included a large number of publications from  
49 diverse authors and perspectives, focused on several different topics and subsets of the  
50 CHIWOS participant population. This increased the reliability of the findings and  
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3 ensured a full picture of the CHIWOS population's experiences was represented in the  
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5 concept maps. Further strengthening this representation was the iterative and community-  
6  
7 based nature of the concept mapping process itself. The process was entirely driven by a  
8  
9 diverse group of community members who amended the maps and diagrams through  
10  
11 several rounds of consultations, which ensured their accuracy.  
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15 In addition to the many strengths, there were some limitations of this study.  
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17 Although efforts were made to engage lead investigators and community researchers  
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19 from all provinces included in the CHIWOS study, only individuals from Ontario and  
20  
21 British Columbia participated in the focus group discussions. However, six manuscripts  
22  
23 with the first author from Quebec were included in production of concept maps. Another  
24  
25 limitation of the study was the exclusion of qualitative manuscripts which hold rich data.  
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27 A reason for this decision was the challenges in the consistency of scoring schemes  
28  
29 needed for concept mapping, which has been highlighted in the literature.<sup>24,28</sup>  
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32 Additionally, we recognize that given the unique perspectives of Indigenous women  
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34 living with HIV, that the creation of an Indigenous-specific summary diagram would  
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36 have strengthened our study. We did not create this diagram due to the lack of  
37  
38 quantitative publications specifically focused on Indigenous women who participated in  
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40 CHIWOS at the time of concept mapping analysis. In keeping with the First Nations  
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42 principles of ownership, control, access and possession (OCAP)<sup>29</sup>, the ownership of  
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44 CHIWOS data from Indigenous women was transferred to Indigenous partners in through  
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46 ceremony in 2017.<sup>31</sup> From the inception of CHIWOS, Indigenous women have prioritized  
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48 community-based knowledge translation activities, including several fireside chats,  
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51 gatherings and posters to share Indigenous CHIWOS findings with community over  
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3 more traditional methods of academic knowledge translation outputs, such as manuscript  
4 or abstract production.<sup>32</sup> However, since the concept mapping interviews were held, the  
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6 CHIWOS-PAW (Positive Aboriginal Women) team of Indigenous leaders published a  
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8 manuscript on findings from the CHIWOS-PAW sub-study using arts-based research  
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10 methods, Indigenous teachings and Ceremony, and Sharing Circles to gather Indigenous  
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12 women's perspectives and experiences of their health and healthcare.<sup>33</sup> Another  
13  
14 manuscript examining findings from the Indigenous women who participated in  
15  
16 CHIWOS is forthcoming, led by Indigenous scholars.  
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22 Recently, other CHIWOS investigators used mapping techniques to examine the  
23  
24 experiences of women living with HIV in accessing care. Skerritt et al.<sup>34</sup> used Fuzzy  
25  
26 Cognitive Mapping, a participatory research method, to identify factors influencing  
27  
28 satisfaction with HIV care in order to understand women's engagement in the HIV care  
29  
30 cascade. Several similarities exist between our approaches to mapping. For instance,  
31  
32 Skerritt et al.'s concept map #2 (HIV Care Concept Map) shows the relationships among  
33  
34 access to care, comprehensive care, and feelings of stigma.<sup>34</sup> Our study is unique as it  
35  
36 includes concept maps related to quality of life, psychosocial and mental health, sexual  
37  
38 health, reproductive health, and trans women with HIV, and also provides the  
39  
40 perspectives from women in Ontario in addition to those in Quebec and British  
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42 Columbia. Both studies provide valuable visual insights into women's experiences and  
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44 complement each other.  
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50 Further, the results of the concept maps identified the need for policy options and  
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52 interventions to address women's health gaps and needs. The two summary diagrams  
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54 demonstrate the need for prioritization of social support, leadership, and capacity-  
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3 building for women living with HIV across all system levels. They highlight the  
4  
5 importance of addressing intersecting social determinants of health to improve health  
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7 outcomes for women living with HIV. The next steps for policy advocacy are the co-  
8  
9 development of a national WCHC<sup>35</sup> strategy that ensures equitable access to care  
10  
11 including gender affirmation, and resource creation and education to increase knowledge  
12  
13 about the health care gaps women living with HIV experience in Canada.  
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15

## 16 17 **Conclusion**

18  
19 We developed a unifying summary of the health experience of women living with  
20  
21 HIV in Canada by applying concept mapping to 59 CHIWOS publications. The produced  
22  
23 visuals can be used to inform policy and programming by providing easy to understand  
24  
25 evidence on gaps related to the social determinants of health including housing, food  
26  
27 security, and income, in addition to structural barriers such as multiple areas of  
28  
29 discrimination. Importantly, these visuals promote strength-based approaches to women  
30  
31 living with HIV's health and wellbeing such as increasing access to WCHC care and self-  
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33 care through positive healthy actions in a way that is accessible to all audiences. The  
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35 results of this study should guide future research and care priorities for women living  
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37 with HIV in Canada.  
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7  
8 study. The authors would also like to thank LJ from The Public Studio for their  
9  
10 collaboration in creating the two summary diagrams.  
11

### 12 **Contributions**

13  
14 AY, PM, MK and ML contributed to the study conception and design. AY, PM, MK, and  
15  
16 BG contributed to the preparation, participant recruitment, and publication screening  
17  
18 process. AY, PM, MK, and ML participated in the development of concept maps and  
19  
20 summary diagrams. PM, JK, and ML wrote the first draft of the manuscript. PF, YP, NO,  
21  
22 BG, BB, SS, MN, AF, BG, CC, KW, MS, AL, CL, AP, AK, and ML provided feedback  
23  
24 and edits on all the visuals and versions of the manuscripts. All authors have read and  
25  
26 agreed to the published version of the manuscript.  
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30  
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32  
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34  
35 supported through a CTN Postdoctoral Fellowship Award from the CIHR Canadian HIV  
36  
37 Trials Network under Grant CTN 262 at the time of this study.  
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40 **Competing Interests:** None declared.  
41

42 **Patient Consent:** Obtained  
43

44 **Patient and public involvement:** Patients and/or the public were involved in the design,  
45  
46 conduct, or dissemination plans of this research. Refer to the Methods for further details.  
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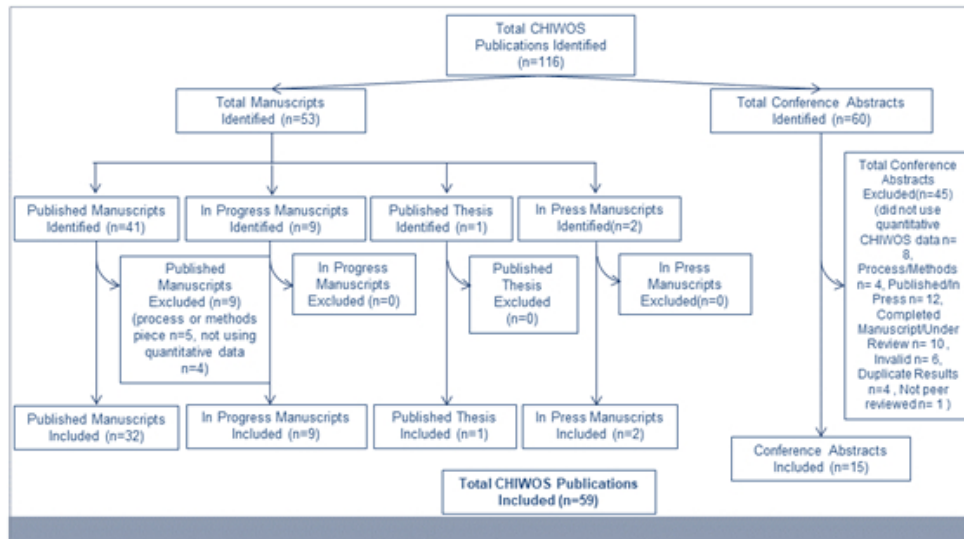


Figure 1: Applying the Eligibility Criteria to the CHIWOS Publications

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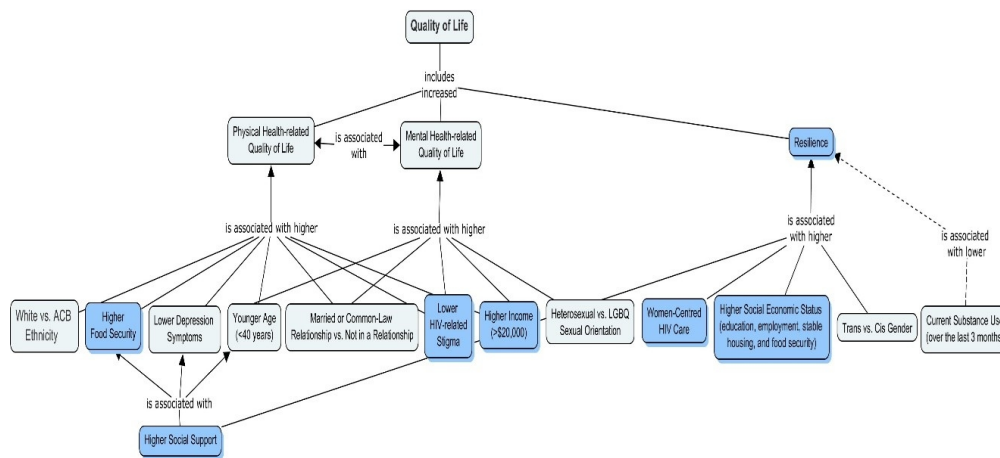


Figure 2: Quality of Life Concept Map

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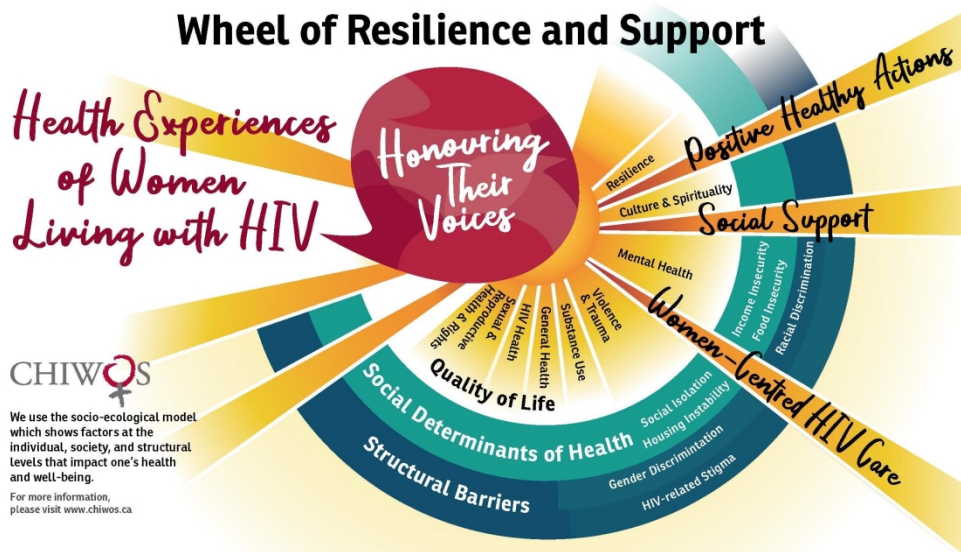


Figure 3: CHIWOS Summary Diagram – Honouring the Experiences of Women with HIV

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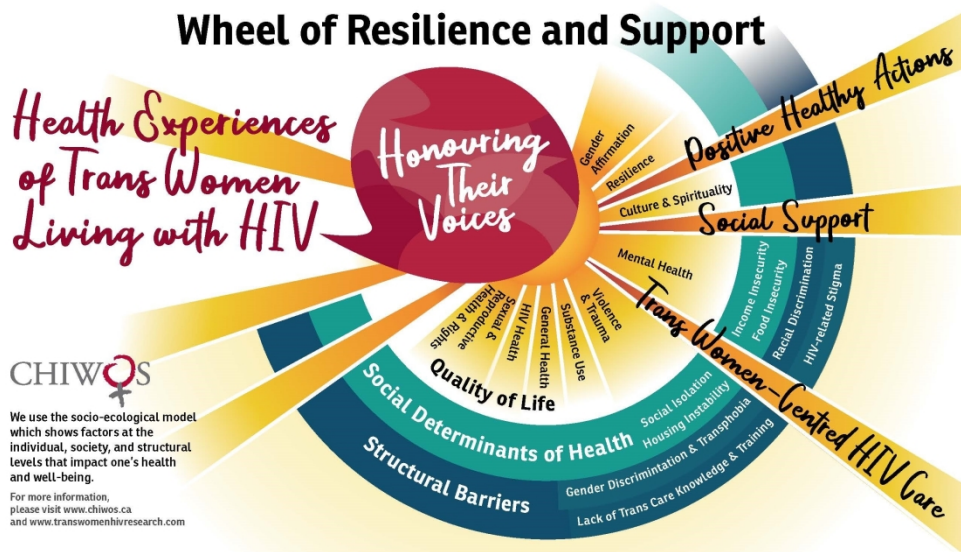


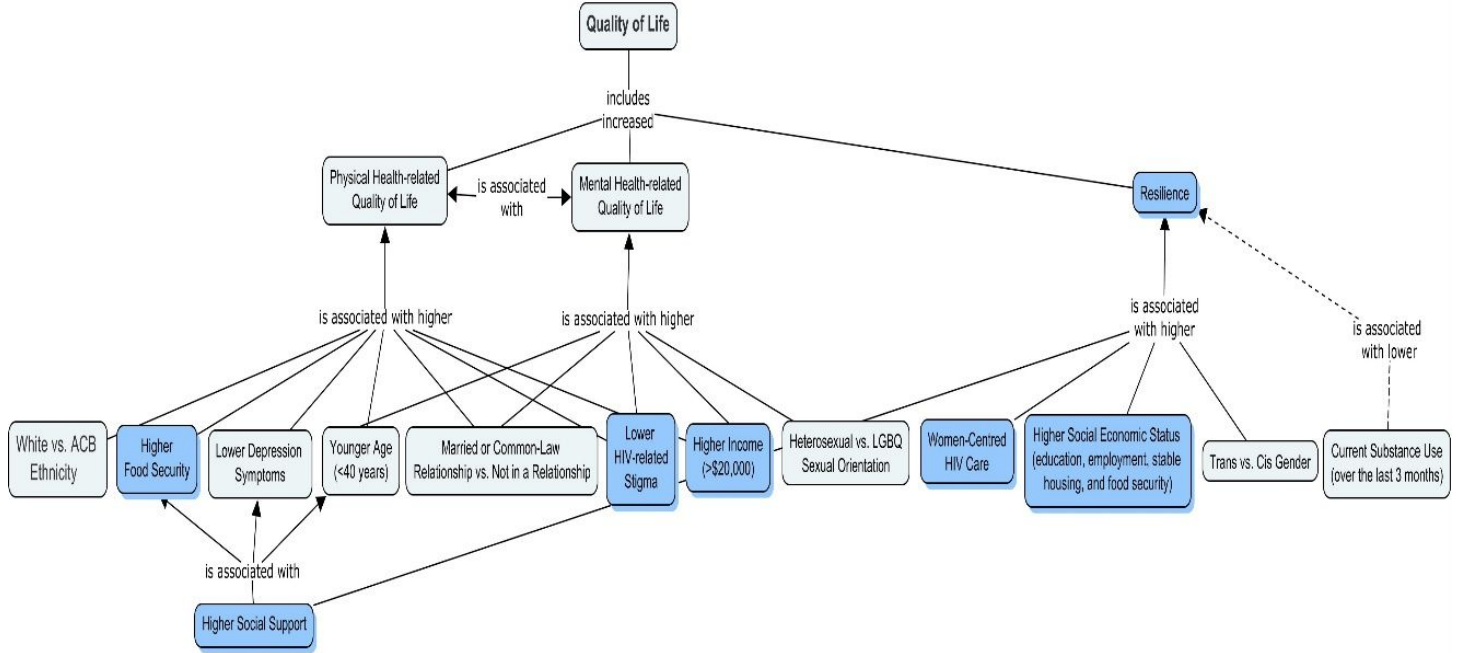
Figure 4: CHIWOS Summary Diagram – Honouring the Experiences of Trans Women Living with HIV

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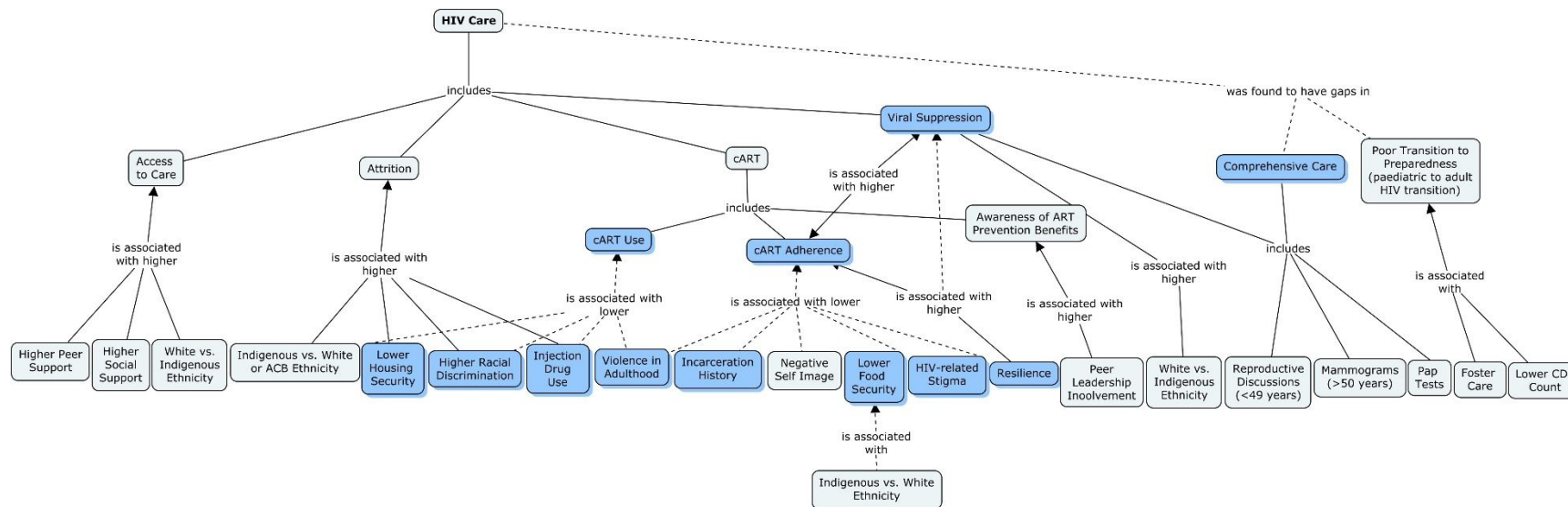
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**Supplementary Figures**  
**Supplemental Figure 1: Quality of Life Concept Map**



Our definition of Quality of Life (QOL) extends beyond one’s physical and mental health status. It is expanded to also include QOL’s relationship with resilience and overall wellbeing. QOL was measured using the SF-12 scale.

Supplemental Figure 2: HIV Care Concept Map

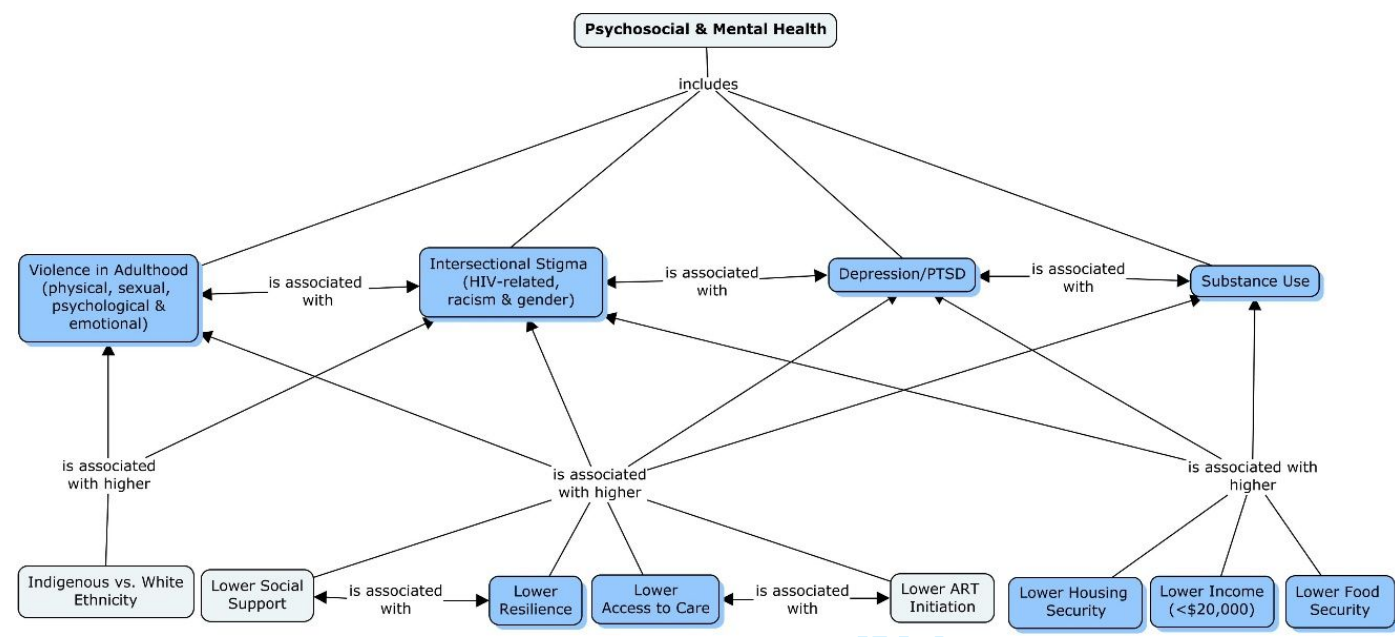


Attrition refers to reduction in the % at each stage of the HIV care cascade. These stages are: 1) access to care, 2) cART use, 3) cART adherence, and 4) viral suppression.

Comprehensive care is defined by four indicators: Pap test, viral load suppression, reproductive discussions, and mammograms.

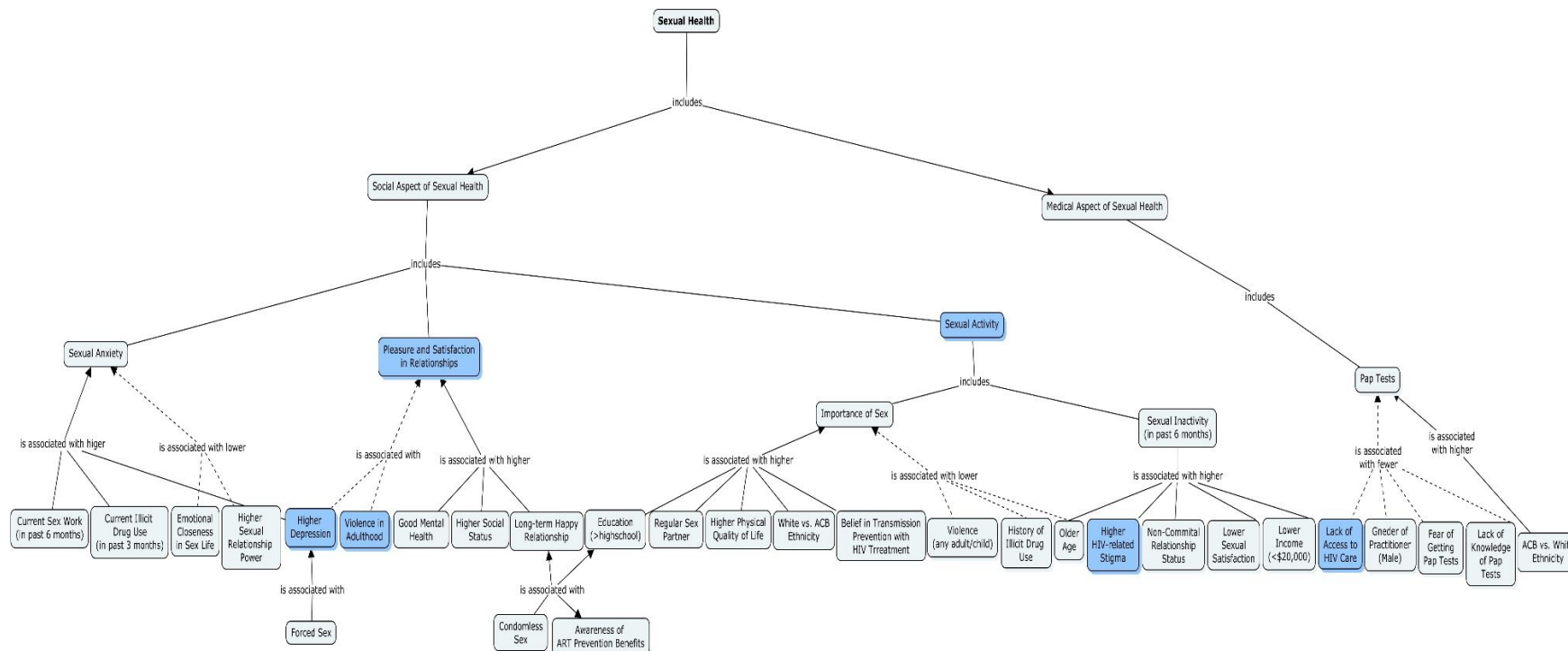
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**Supplemental Figure 3: Psychosocial and Mental Health Concept Map**



Intersectional stigma, violence, depression/PTSD, and substance use are associated with each other. Also, access to care was measured using the Barriers to Access to Care 12-item scale.

Supplemental Figure 4: Sexual Health Concept Map

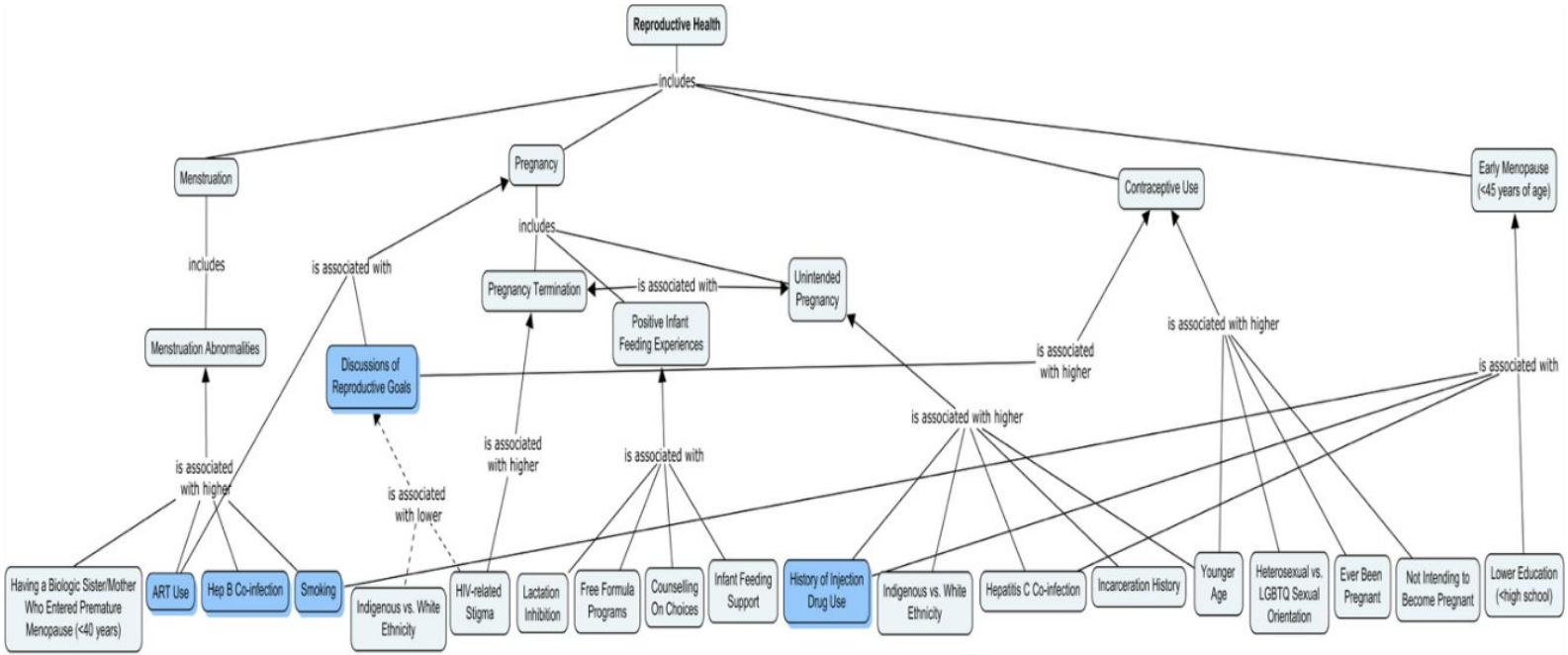


There are various medical aspects of sexual health, including the experiences and management of sexually transmitted infections; however, CHIWOS has not yet analyzed data on them.

Sexual activity was defined as consensual sex (oral or penetrative) in the past six months based on the questionnaire used; but it is understood to represent much more including sexual desire, sexual needs, sexual being, and more.

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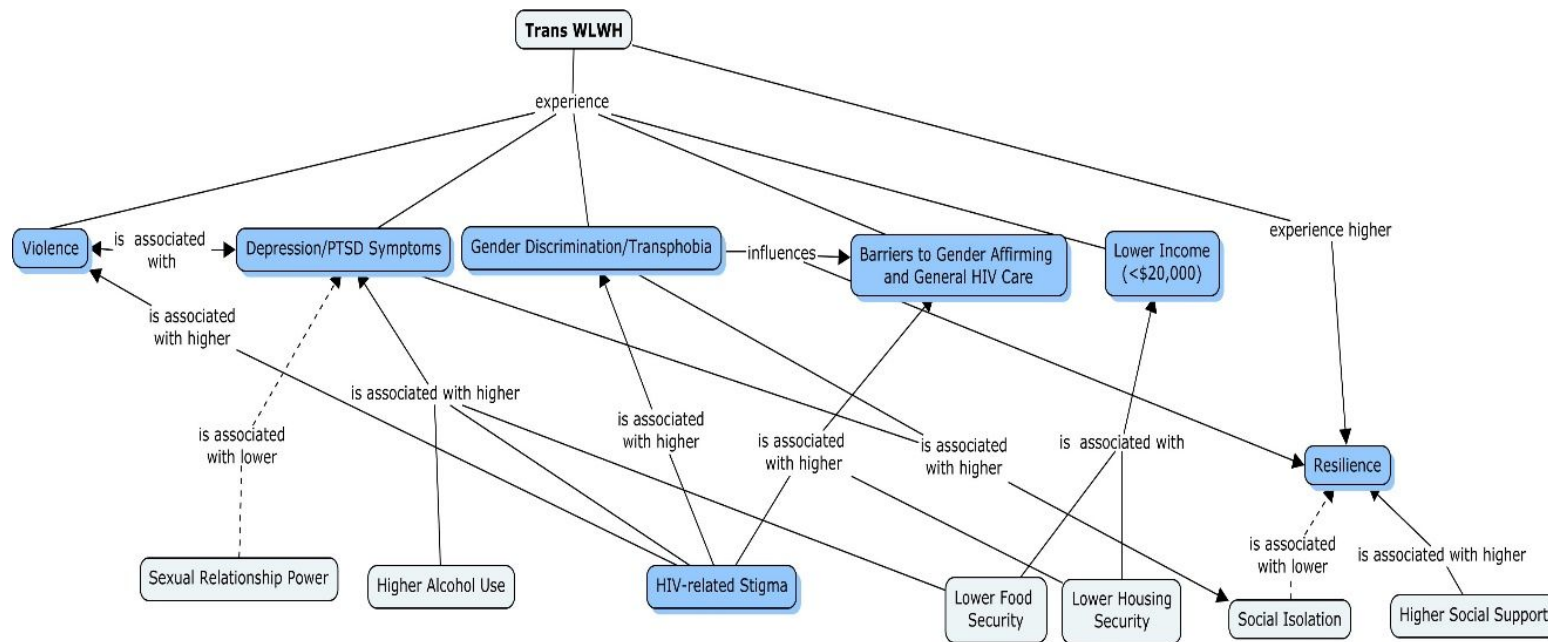
Supplemental Figure 5: Reproductive Health Concept Map



CHIWOS findings showed a narrow range of contraceptive methods used.

only

Supplemental Figure 6: Trans WLWHIV Concept Map



Social isolation is the absence of social and economic supports (i.e., lower income, housing, and food services) which are barriers to ongoing engagement in HIV care. These variables are in comparison to cis-gender women.

# BMJ Open

## Experiences and resultant care gaps among women with HIV in Canada: Concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) Findings

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Manuscript ID	bmjopen-2023-078833.R1
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Date Submitted by the Author:	07-Feb-2024
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<b>Primary Subject Heading</b>:	HIV/AIDS
Secondary Subject Heading:	Health services research, Patient-centred medicine, Sexual health
Keywords:	HIV & AIDS < INFECTIOUS DISEASES, Health Equity, Patient-Centered

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	Care, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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3 Experiences and resultant care gaps among women with HIV in Canada: Concept  
4 mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study  
5 (CHIWOS) Findings  
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7  
8 **Abstract**  
9

10 **Objectives:** The community-based, longitudinal, Canadian HIV Women's Sexual and  
11 Reproductive Health Cohort Study (CHIWOS) explored the experiences of women with  
12 HIV in Canada over the past decade. CHIWOS' high impact publications document  
13 significant gaps in the provision of health care to women with HIV. We used concept  
14 mapping to analyse and present a summary of CHIWOS findings on women's  
15 experiences navigating these gaps.  
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24 **Design:** Concept mapping procedures were performed in two steps between June 2019  
25 and March 2021. First, two reviewers (AY and PM) independently reviewed CHIWOS  
26 manuscripts and conference abstracts written before 1 August 2019 to identify main  
27 themes and generate individual concept maps. Next, the preliminary results were  
28 presented to national experts, including women with HIV, to consolidate findings into  
29 visuals summarizing the experiences and care gaps of women with HIV in CHIWOS.  
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38 **Setting:** British Columbia, Ontario and Quebec, Canada.  
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40 **Participants:** A total of 18 individual CHIWOS team members participated in this study  
41 including six lead investigators of CHIWOS and 12 community researchers.  
42  
43

44  
45 **Results:** Overall, a total of 60 peer-reviewed manuscripts and conference abstracts met  
46 the inclusion criteria. Using concept mapping, themes were generated and structured  
47 through online meetings. In total, six concept maps were co-developed: quality of life,  
48 HIV care, psychosocial and mental health, sexual health, reproductive health, and trans  
49 women's health. Two summary diagrams were created encompassing the concept map  
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3 themes, one for all women and one specific to trans women with HIV. Through our  
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5 analysis, resilience, social support, positive healthy actions, and women-centred HIV care  
6  
7 were highlighted as strengths leading to well-being for women with HIV.  
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10 **Conclusions:** Concept mapping resulted in a composite summary of 60 peer-reviewed  
11  
12 CHIWOS publications. This activity allows for priority setting to optimize care and well-  
13  
14 being for women with HIV.  
15

16  
17 **Keywords:** HIV, women's health, healthcare systems, care gaps, concept mapping  
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### 22 **Strengths and limitations of this study**

- 23  
24 ● The study comprehensively summarizes the health experiences of women with  
25  
26 HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health  
27  
28 Cohort Study (CHIWOS) and identifies potential gaps in their care.  
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- 30  
31 ● A diverse group of women and HIV experts across Canada took part in this study  
32  
33 to provide feedback on the concept maps which used results from 60 peer-  
34  
35 reviewed publications by, with and for women with HIV.  
36  
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- 38 ● Between June 2019 and March 2021, the process of concept mapping and  
39  
40 reviewing visualizations with key informants took place. No new publications  
41  
42 developed after the cut-off date of August 1, 2019 could be included in this  
43  
44 analysis. However, manuscripts under review or near publication were included  
45  
46 and have all since been published.  
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- 49 ● Although efforts were made to engage team members from all provinces included  
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51 in the CHIWOS study, only community researchers from Ontario and British  
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3 Columbia agreed to take part in this study, though academic researchers from  
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5 Quebec participated.  
6

## 7 8 **Introduction**

9  
10 Recent studies have found that women with HIV experience unique health and  
11  
12 social needs that differ from those of men with HIV and limit their access to treatment  
13  
14 and care services (1-3). The historical lack of research focusing on the realities of women  
15  
16 with HIV may be detrimental to their health (4,5). These circumstances led to the  
17  
18 development and implementation of the Canadian HIV Women's Sexual and  
19  
20 Reproductive Health Cohort Study (CHIWOS) – the largest community-based study in  
21  
22 Canada exploring the experiences and priorities of a diverse, national cohort of women  
23  
24 with HIV in British Columbia (BC), Ontario (ON), and Quebec (QC) from 2013-2018.  
25  
26

27  
28 CHIWOS was initiated in 2011 through a qualitative phase, which informed the  
29  
30 creation of an in-depth survey (1,2). The study's objectives were to examine women's  
31  
32 access to women-centred HIV care and the impact of corresponding usage patterns on  
33  
34 health outcomes (2). CHIWOS was guided by principles of equitable involvement of  
35  
36 those affected *by* the research *in* the research process by establishing community-  
37  
38 academic partnerships and shared decision-making throughout the study (6,7). This  
39  
40 research approach, reflecting community-based research (CBR) values, was enacted in  
41  
42 part through the involvement of women with HIV as trained community researchers to  
43  
44 conduct research activities in each stage of the project (2,8,9). CHIWOS was created by,  
45  
46 with, and for women with HIV in collaboration with academic researchers, clinicians,  
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48 and community partners to investigate women's mental, sexual and reproductive health  
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50 care priorities, and need for a women-centred HIV care model (1,2,10). Cohort data  
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3 collection was launched in 2013 and collected at three time points, 18 months apart,  
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5 from August 2013 to September 2018. A complete description of CHIWOS can be found  
6  
7 at [www.chiwos.ca](http://www.chiwos.ca). As of publication acceptance, CHIWOS remains the largest  
8  
9 longitudinal study of women with HIV in Canada, successfully enrolling a diverse cohort  
10  
11 of 1,422 women with HIV (356 from BC [25%], 713 from ON [50%], and 353 from QC  
12  
13 [25%]) (1,2).  
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17 As of August 2019, a total of 113 publications (53 manuscripts and 60 conference  
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19 abstracts) had been written using CHIWOS data. This academic content explores dozens  
20  
21 of specific topics related to the experiences of women with HIV, including psychosocial  
22  
23 determinants, clinical, mental, sexual, and reproductive health outcomes, as well as  
24  
25 access to, and quality of healthcare that characterize women's health gaps and needs and  
26  
27 that can be used to inform programming and policy in Canada. In an effort to better  
28  
29 understand the main topics and gaps of CHIWOS manuscripts and conference abstracts,  
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31 this study applied Novak and Gowin's (1984) concept mapping methodology (11). The  
32  
33 goal of this methodology was to visualize concepts of CHIWOS findings in a hierarchical  
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35 fashion, with the most inclusive and general concepts at the top of the map, and specific  
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37 concepts arranged hierarchically below to represent the inter-related relationships in each  
38  
39 publication included. We sought to apply these findings towards the creation of a  
40  
41 summary diagram to summarize the health experiences and gaps of women with HIV  
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43 enrolled in CHIWOS. An added benefit of using concept mapping in this study is that the  
44  
45 simplistic visualizations allowed for increased accessibility of the CHIWOS findings to  
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47 those outside of academia, including some community members and knowledge users,  
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49 which enabled shared decision-making to inform the final product. Our goal was to use  
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3 these findings to characterize women with HIV's healthcare needs and gaps to inform  
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5 policy and programming in Canada.  
6

## 7 8 **Methods**

9  
10 Concept mapping is a graphical methodology used to organize and present  
11  
12 knowledge. Since its conception by Novak (1974) (12), it has been adapted in qualitative  
13  
14 research to present findings and analyze themes (13,14). This methodology was chosen to  
15  
16 illustrate the key themes from the CHIWOS publications, including both manuscripts and  
17  
18 conference abstracts, and their relation to each other in order to demonstrate the  
19  
20 experiences and related gaps in care women with HIV face in Canada. We used a social-  
21  
22 ecological perspective to understand the interplay between multi-level factors impacting  
23  
24 women with HIV, their community, and society (15-17).  
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28 For this study, the concept mapping process from Novak (1998) (18) was used  
29  
30 and encompassed five steps:  
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34 **Step 1:** Conduct a thematic analysis on CHIWOS publications and summarize key  
35  
36 findings  
37

38 All CHIWOS publications (including manuscripts and conference abstracts)  
39  
40 published, under review, or near publication submission before 1 August 2019 were  
41  
42 examined alongside inclusion criteria developed by the core concept team (including AY,  
43  
44 MK, ML, and PM). To be included for review, manuscripts were to 1) include national  
45  
46 quantitative CHIWOS questionnaire data, and 2) be published, under review or near  
47  
48 submission in a peer-reviewed journal (manuscripts) or be presented at a HIV-related  
49  
50 conference (abstracts) by the exclusion date.  
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Manuscripts that did not use quantitative CHIWOS data or were process or methods pieces were excluded. For conference abstracts, those which had been published or submitted as manuscripts, showed duplicate results to other abstracts, or were not peer-reviewed prior to conference presentation were excluded. Figure 1 shows the selection process. A total of 113 CHIWOS publications (including manuscripts and conference abstracts) were reviewed, of which 53 were excluded. This resulted in 60 eligible publications that met the inclusion criteria (summarized in Table 1). Eligible publications were grouped together by their overarching theme (discussed further in step 3).

[insert Figure 1 here]

**Table 1:** Summary of Included CHIWOS Publications

Concept Map Theme	Manuscripts (n=44)	Conference Abstracts (n=16)
Quality of life	n=4 (a) <a href="#">Logie, Wang et al. 2018</a> <a href="#">Carter, Loutfy et al. 2018</a> <a href="#">Kteily-Hawa, Andany et al. 2019</a> <a href="#">Kteily-Hawa, Warren et al. 2019</a>	
HIV care	n=8 <a href="#">Kennedy, Mellor et al. 2020</a> <a href="#">Kerkerian, Kestler et al. 2018</a> (a) <a href="#">Kronfli, Lacombe-Duncan et al. 2017</a> (b) <a href="#">Kronfli, Lacombe-Duncan et al. 2017</a> (b) <a href="#">Logie, Wang et al. 2018</a> <a href="#">Loutfy, de Pokomandy et al. 2017</a> <a href="#">O'Brien, Godard-Sebillotte et al. 2019</a> (a) <a href="#">Shokoohi, Bauer et al. 2019</a>	n=4 Conway, Gormley et al. 2019 Kaida, Conway et al. 2019 Loutfy, de Pokomandy et al. 2015 Puskas, Pick et al. 2018
Psychosocial & mental health	n=14 <a href="#">Carter, Roth et al. 2018</a> <a href="#">Churchill. 2018</a> <a href="#">Gormley, Nicholson al. 2021</a> <a href="#">Heer, Kaida et al. 2022</a>	n=5 Kaida, Nicholson et al. 2019 (a) Logie, Wang et al. 2019 (b) Logie, Wang et al. 2019

	<a href="#">Jaworsky, Logie et al. 2018</a> (a) <a href="#">Logie, Lacombe-Duncan et al. 2018</a> <a href="#">Logie, Marcus et al. 2019</a> (c) <a href="#">Logie, Wang et al. 2018</a> <a href="#">Logie, Williams et al. 2019</a> <a href="#">Patterson, Nicholson et al. 2020</a> <a href="#">Shokoohi, Bauer et al. 2018</a> (b) <a href="#">Shokoohi, Bauer, et al. 2019</a> (c) <a href="#">Shokoohi, Bauer et al. 2019</a> <a href="#">Wagner, Jaworsky et al. 2018</a>	Parry, Lee et al. 2019 Underhill, Wu et al. 2018
Sexual health	n=8	n=2
	(a) <a href="#">Carter, Greene et al. 2018</a> (b) <a href="#">Carter, Greene, et al. 2018</a> <a href="#">Carter, Greene et al. 2019</a> <a href="#">Carter, Patterson et al. 2020</a> <a href="#">de Pokomandy, Burchell et al. 2019</a> <a href="#">Kaida, Carter et al. 2015</a> <a href="#">Logie, Kaida et al. 2020</a> <a href="#">Patterson, Carter et al. 2017</a>	Salters, Loutfy et al. 2015 Underhill, Kennedy et al. 2017
Reproductive health	n=6	n=4
	<a href="#">Andany, Kaida et al. 2020</a> <a href="#">Fortin-Hughes, Proulx-Boucher et al. 2019</a> <a href="#">Kaida, Patterson et al. 2017</a> <a href="#">Salters, Loutfy et al. 2017</a> <a href="#">Skeritt L, de Pokomandy et al. 2021</a> <a href="#">Valiaveetil, Loutfy et al. 2019</a>	Boucoiran, Kaida et al. 2019 Kaida, Gormley et al. 2019 Kaida, Money et al. 2017 Siou, Salters et al. 2016
Trans women with HIV	n=4	n=1
	<a href="#">Lacombe-Duncan, Bauer et al. 2019</a> <a href="#">Lacombe-Duncan, Newman et al. 2017</a> <a href="#">Lacombe-Duncan, Warren et al. 2021</a> (b) <a href="#">Logie, Lacombe-Duncan et al. 2018</a>	Lacombe-Duncan, Persad et al. 2017

See Supplementary Material for full citations.

From the 60 included manuscripts and conference abstracts, we began by identifying the major findings of each that answered the guiding question: what



1  
2  
3 characterizes the healthcare gaps and needs of CHIWOS participants? We examined  
4 publications to identify themes related to gaps in care, as well as explicit findings related  
5 to healthcare access and quality. We then used the coding step of a thematic analysis (19)  
6 to code the findings into their simplest form (e.g., lower food security is associated with  
7 increased substance use). As a last step, we listed the concepts and linking words within  
8 each code (e.g., concepts = lower food security, substance use; linking words = is  
9 associated with) (19). This process was repeated for each manuscript and conference  
10 abstract. In our efforts to mitigate theme overrepresentation, we opted to include an  
11 abstract only when a corresponding manuscript was not available. However, given the  
12 inherent intersectionality of the data, there may be instances where subsets of the data  
13 were presented in multiple publications. A thorough exploration of such cases is provided  
14 in the discussion section for clarity and transparency.

## 31 **Step 2: Individual concept mapping of CHIWOS manuscripts and abstracts**

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33  
34 The concepts and linking words from Step 1 were used to guide the design of 60  
35 individual concept maps, each visually summarizing the key findings of one manuscript  
36 or conference abstract. Figure 2 is an example of one of the individual concept maps we  
37 created from the CHIWOS findings.

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40  
41 **[insert Figure 2 here]**

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45 Within each map, concepts were listed in hierarchical order with the most  
46 overarching general concepts at the top and the most specific concepts at the bottom (11).  
47 Using an online software, CMAPTools (20), concepts were designated by boxes and lines  
48 were drawn from one concept to another with the linking words placed in between. We  
49 adapted the concept map process by adding in extra features that better visually represent

1  
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3 the CHIWOS findings. For example, arrowheads pointed towards outcomes of CHIWOS  
4 findings. Bi-directional arrows were used when a relationship was present between two  
5 outcomes. Solid lines represented a positive association between concepts while dotted  
6 lines represented a negative association between concepts. Concepts that recurred in two  
7 or more individual concept maps were considered critical findings and were designated  
8 by a blue shaded concept box.  
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AY and PM independently reviewed each concept map to ensure all major findings were represented and summarized into the visual. If there was a discrepancy, a third reviewer (ML) was consulted to make the final decision.

### **Step 3:** Compilation of individual concept maps into composite concept maps

AY, PM, and ML grouped the maps with main concepts and similar themes together. Six major themes were identified: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women with HIV.

The individual concept maps that fell under each major theme were compiled together to create a composite concept map. AY and PM drew cross-links between concepts that had relationships but were on different domains of the composite concept map (14). This process was repeated for each theme and six composite concept maps were developed.

### **Step 4:** Internal development team review and brainstorming of overarching visualization

An internal team (including AY, MK, ML, and PM) meeting was held in August 2019 to review all six composite concept maps. The goal was to ensure all key findings were represented on the maps with good readability. The guiding question was referred to when deciding to remove or add concepts to the map. The team then brainstormed ideas

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3 to design a compilation visual representing the findings of the six composite maps that  
4 answered our guiding research question. A preliminary sketch was formed which is now  
5 referred to as the summary diagram.  
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#### 10 11 **Step 5: External expert team review and validation**

12  
13 The first author of each included CHIWOS manuscript and conference abstract  
14 (herein referred to as lead investigators), and all CHIWOS community researchers were  
15 identified as potential key participants in this study and were approached for recruitment  
16 from October 2019 to November 2020. Over 30 CHIWOS academic and community  
17 team members from all three provinces were invited to participate in the study by email.  
18 A total of 29 meetings were held with groups of participants and took place both in-  
19 person and virtually.  
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29 For orientation, introductory slides explaining the concept mapping methodology  
30 and its application to CHIWOS findings were shown to the group. Each of the six  
31 composite concept maps were then presented. Lead investigators were asked to ensure  
32 that all major CHIWOS findings were accurate and present, and community researchers  
33 were asked to ensure that the experiences of women with HIV were accurately  
34 represented. All participants were asked to provide input on the readability, clarity, and  
35 inclusivity of language. Next, the summary diagram was presented, and participants were  
36 asked to ensure that all key components from the composite concept maps were included  
37 in the summary diagram, in addition to providing feedback on design features including  
38 colour, layout, and display of content. All participant feedback was documented and the  
39 feedback between different focus groups were compared. All suggestions and changes  
40 were reviewed by AY and PM through revisiting the manuscript and abstracts and  
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3 addressing the guiding research question. Updated composite theme maps and the  
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5 summary diagrams were presented at a follow-up meeting and consensus was reached by  
6  
7 discussion.  
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9

### 10 **Ethics Approval**

11  
12 The study was assessed by the research ethics board at Women's College Hospital  
13  
14 to not require ethical approval by a human research ethics committee because the Ethical  
15  
16 Principles for Medical Research Involving Human Subjects did not apply. Instead,  
17  
18 participants, all of whom had been previously engaged as CHIWOS research team  
19  
20 members participated as research consultants to the concept process on a volunteer basis.  
21  
22 We obtained informed consent from all participants.  
23  
24  
25

### 26 **Patient and Public Involvement**

27  
28 Evidently, women with HIV (community researchers; those previously involved  
29  
30 in the CHIWOS project) Their invaluable insights significantly contributed to the  
31  
32 thematic analysis and individual concept mapping, offering a nuanced perspective on  
33  
34 healthcare gaps and needs. Additionally, their active participation in validating composite  
35  
36 concept maps and the summary diagram guaranteed precision and inclusivity in the  
37  
38 representation of findings. In recognition of their contributions, all community members  
39  
40 involved were appropriately compensated for their time and expertise.  
41  
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44

### 45 **Results**

46  
47 A total of 18 individuals participated in the design and review of the concept  
48  
49 maps, including six academic investigators (BC: n=1; ON: n=3; QC: n=2), and 12  
50  
51 community researchers (BC: n=5; ON: n=7). All participants identified as cis or trans  
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53 women.  
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## Composite Concept Maps

Overall, six composite maps were created (see Supplementary Figures 1-6).

We developed composite map 1 (see Supplementary Figure 1) from four manuscripts focused on the topic of quality of life. Notable findings in this concept map include bi-directional association of physical and mental health quality of life, and the association of experiences of women-centred HIV care with higher resilience and in turn higher quality of life. This map illustrates the influence socioeconomic status, experiences of stigma, sexual orientation, substance use, social support, and relationship status have on mental and physical health-related quality of life.

From eight manuscripts and four conference abstracts, map 2 (see Supplementary Figure 2) was created to illustrate findings related to HIV care. This map demonstrates associations between several aspects of HIV care including viral suppression, use of combination antiretroviral therapy (cART), care access and attrition. Notable findings include the effect having social and peer support have on increasing access to HIV care and the effect of racial discrimination on care attrition. Experiencing violence in adulthood was found to reduce cART use and adherence, leading to reduced viral suppression. On the other hand, peer leadership involvement was associated with higher awareness of cART prevention benefits.

Map 3 (see Supplementary Figure 3) demonstrates the connections between various facets of psychosocial and mental health and represents data from 14 manuscripts and five abstracts. Indigenous heritage was associated with experiencing higher violence in adulthood as well as lower housing security and income. Lower food security was associated with higher substance use. This map emphasizes the negative impact of

1  
2  
3 intersectional stigma on all aspects of mental health, which are associated with clinical  
4  
5 measures like a lack of cART initiation.  
6

7  
8 The most complex of the six visuals is map 4 (see Supplementary Figure 4) which  
9  
10 explores sexual health experiences of women enrolled in CHIWOS. This map represented  
11  
12 data from eight manuscripts and two abstracts. Its findings were organized into social and  
13  
14 medical aspects of sexual health sub-categories. A main finding was the association of  
15  
16 higher depression and experienced violence in adulthood with lower pleasure and  
17  
18 satisfaction in relationships. Higher HIV-related stigma was also associated with higher  
19  
20 sexual inactivity in the past six months, which was a recurring theme in the included  
21  
22 publications.  
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26 The fifth map (see Supplementary Figure 5) showed CHIWOS findings related to  
27  
28 reproductive health. The production of this map as separate from sexual health was  
29  
30 intentional to illustrate that for many women, sexual health goes beyond reproductive  
31  
32 health desires or lack thereof. This map drew on data from six manuscripts and four  
33  
34 abstracts, and includes sub-categories of menstruation, pregnancy, contraceptive use, and  
35  
36 early menopause. Findings showed low use of a narrow range of contraceptive methods,  
37  
38 with sexual orientation, previous pregnancies, and age influencing contraceptive choice.  
39  
40 Service provider counselling on choices for infant feeding practices, support and free  
41  
42 formula programs were associated with positive infant feeding experiences for women.  
43  
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47 The final map titled Trans Women Concept Map (see Supplementary Figure 6)  
48  
49 included topics from all five of the other concept maps but from the exclusive perspective  
50  
51 of trans women in CHIWOS, with data drawn from four manuscripts and one abstract  
52  
53 that solely analysed trans women's data. This map shows trans women's experiences of  
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3 gender discrimination and transphobia, which influence barriers to gender affirming and  
4  
5 general HIV care, with HIV-related stigma playing a significant role in this association.  
6  
7 Higher sexual relationship power was associated with lower depression and post-  
8  
9 traumatic stress disorder symptoms. Higher social support was associated with resilience,  
10  
11 which trans women experienced higher levels of than cis women in CHIWOS.  
12  
13

### 14 **Summary Diagrams**

15  
16 From the six composite concept maps, two summary diagrams were created (see  
17  
18 Figures 3 and 4), one for all women and one for trans women specifically. These  
19  
20 diagrams provide a summary of the key insights, barriers, and supports that affect the  
21  
22 health and well-being of women with HIV involved in CHIWOS. Through actively  
23  
24 participating in the arts-based design process of the two summary diagrams, community  
25  
26 researchers played a vital role in shaping both the overall themes presented and the final  
27  
28 visual of the diagrams. They insisted on grounding the diagrams in the stories and  
29  
30 experiences of CHIWOS participants, highlighting the importance of making them  
31  
32 accessible, empowering, holistic, authentic, and inclusive - these specific terms were  
33  
34 consistently used by community researchers during our collaborative meetings as we  
35  
36 worked together on developing the diagrams. The meaningful engagement of community  
37  
38 researchers (who collected the CHIWOS data) ensured women with HIV were  
39  
40 represented and involved in shared decision-making between community and academic  
41  
42 team members in the creation of these diagrams.  
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49 We utilized a socio-ecologic model in developing the summary diagrams to show  
50  
51 how the individual, societal, and structural factors present in the concept maps intersect  
52  
53 to affect women's health and well-being (11-13). To visually represent this intersection,  
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3 the diagram was created in the shape of concentric circles. At the centre of both visuals is  
4 a speaking bubble highlighting the stories that women who participated in CHIWOS  
5 shared and was named by the community researchers: “Honouring Their Voices.” The  
6 inner circle of both figures highlights the aspects that are important to women’s quality of  
7 life: HIV health, general health including physical, health, sexual and reproductive  
8 health, mental health, violence and trauma, substance use, culture and spirituality, and  
9 resilience. Surrounding quality of life are social factors that combine to affect the health  
10 of individuals and their communities, such as housing stability, food security, income,  
11 and social isolation. The outer circle consists of the structural factors that affect health  
12 including HIV-related stigma, and gender and racial discrimination. Intersecting these  
13 layers of the women’s health experiences are the important ways women are addressing  
14 barriers in their lives, including through social support, accessing, or calling to action the  
15 need for women-centred HIV care, and positive healthy actions.  
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33 **[insert Figure 3 here]**  
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35 Through consultations with a trans women advocate and CHIWOS team member,  
36 the second summary diagram (see Figure 4) was created to reflect the most important and  
37 recurring findings of the concept mapping exercise as they relate to the experiences of  
38 trans women with HIV involved in CHIWOS. The main difference from Figure 3 is the  
39 addition of gender affirmation in the inner circle in reference to trans women’s  
40 experiences. Community researchers define gender affirmation whereby an individual  
41 receives the affirmation they desire with respect to their gender identity and expression  
42 from those around them, including social recognition and/or medical access to care such  
43 as hormone therapy and gender-affirming surgeries.  
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3 **[insert Figure 4 here]**  
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5 Together, the concept maps show that there are both commonalities and  
6 differences in the experiences of women with HIV; however, resilience was present  
7 among all CHIWOS participants.  
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12 Through facilitated discussions with The Public Studio, an activist design studio  
13 in Toronto (<https://thepublicstudio.ca/>), we identified that community partners wanted: 1)  
14 a sun to be a theme of the visuals that radiates energetically from the centre of the  
15 diagram and 2) a strength-based title such as the “Wheel of Resilience and Support.” It  
16 was important to the community partners that the visuals served as an invitation to  
17 translate the stories of CHIWOS participants into action.  
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## 26 **Discussion**

27  
28 The six composite concept maps and two summary diagrams show a decade of  
29 work done by the CHIWOS team, providing a dynamic mosaic of information  
30 representative of the intricacies of women’s experiences (11-13). The co-creation of  
31 concept maps, distinct from traditional systematic reviews, offers an innovative and  
32 valuable approach to understanding the health experiences of women with HIV,  
33 providing novel insights that extend beyond individual publications for a more  
34 comprehensive and nuanced understanding of the multifaceted experiences of women  
35 who participated in CHIWOS. The integration of cross-cutting themes like women-  
36 centred HIV care and the importance of positive healthy actions in the summary diagram  
37 visually emphasizes the most crucial issues for future research, thus contributing to the  
38 advancement of policy and programming for women with HIV in Canada.  
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3 A main strength of this study is the richness of CHIWOS dataset analyses  
4  
5 conducted over the last 10 years. This study included publications from diverse authors  
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7 and perspectives and focused on different topics and subsets of the CHIWOS participant  
8  
9 population. This increased the reliability of the findings and ensured a full picture of the  
10  
11 CHIWOS population's experiences was represented in the concept maps. Further  
12  
13 strengthening this representation was the iterative and community-based nature of the  
14  
15 concept mapping process itself. The process was driven by a diverse group of  
16  
17 community members who amended the maps and diagrams through several rounds of  
18  
19 consultations, which ensured their accuracy. While we recognize that the inclusion of  
20  
21 publications under review or nearing publication may be perceived as a potential  
22  
23 limitation due to the absence of peer review, we primarily interpret this as a strength.  
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25 This decision allowed us to account for the inherent time lag between research analysis  
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27 and formal publication, ensuring our analysis captures both established and emerging  
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29 insights in the field. Furthermore, all "in progress" manuscripts included in this analysis  
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31 have since been published, affirming the validity of our conclusions.  
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38 To prevent theme overrepresentation, we carefully examined the content of each  
39  
40 conference abstract and publication to ensure duplicate results were not included. Some  
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42 publications covered similar themes, such as disclosure, pregnancy loss, cervical cancer  
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44 disparities, women-centred HIV care, help-seeking, the relationship between stigma and  
45  
46 other factors, conception in serodiscordant couples, and issues specific to trans women.  
47  
48 However, there were nuanced differences with each of these themes. For instance, the  
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50 conference abstract focused on disclosure specifically addresses disclosure worries as a  
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52 factor contributing to health outcomes, while the manuscripts explore experienced child  
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3 abuse as a determinant of barriers to disclosure and awareness of the criminalization of  
4 disclosure. We find including these nuanced distinctions valuable, as concepts recurring  
5 in two or more concept maps were considered critical findings. Our rigorous approach to  
6 highlight crucial findings without data overrepresentation is a key strength of this study.  
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12 The co-creation of separate concept maps for cis and trans women shows the  
13 important similarities and differences between cis and trans women's experiences, and  
14 provides a unique perspective not explored in the individual concept maps. Our findings  
15 show many similarities in the health experiences of cis and trans women with HIV in  
16 CHIWOS were shared (21). This is important for providers who often assume providing  
17 care to trans women with HIV requires a unique skillset and approach (22). The key  
18 differences in the summary diagrams were gender affirmation at the individual level, as  
19 well as trans care knowledge and training at the structural level. Obtaining training in  
20 trans health and gender affirmation is a manageable goal that providers can achieve to  
21 deliver more competent care to trans women with HIV (23).  
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35 There are some limitations of this study . Efforts were made to engage lead  
36 investigators and community researchers from all provinces included in the CHIWOS  
37 study, but only academic researchers (not community researchers) from Quebec  
38 participated in this study. However, six manuscripts were included in production of the  
39 concept maps in which the first author was from Quebec and community members were  
40 involved in co-authoring these publications. In shaping our study, we intentionally  
41 excluded manuscripts exclusively featuring qualitative data; a decision that might be seen  
42 as constraining the incorporation of certain insights. This choice was driven by the  
43 inherent challenges of equitably integrating qualitative and quantitative data, especially  
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3 given the marked difference in sample sizes between the two types of manuscripts. To  
4  
5 mitigate this limitation, we extensively involved community researchers in the concept  
6  
7 mapping and summary diagram creation process, ensuring a comprehensive approach.  
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10 Recently, fellow CHIWOS investigators also employed mapping techniques to  
11  
12 examine the experiences of women with HIV in accessing care. Skerritt et al. (24) used  
13  
14 Fuzzy Cognitive Mapping, a participatory research method, to identify factors  
15  
16 influencing satisfaction with HIV care and to understand engagement in the HIV care  
17  
18 cascade. The Summary Fuzzy Cognitive Map they produced shows the weightings of  
19  
20 categories influencing satisfaction of care, with the most significant being feeling safe  
21  
22 and supported by healthcare providers, accessible services, and healthcare provider  
23  
24 expertise (24). These mirror some of our findings in our concept maps 2 and 6 which  
25  
26 show the relationships among access to care, comprehensive care, and feelings of stigma.  
27  
28 Both studies offer valuable visual insights into women's experiences, complementing  
29  
30 each other and contributing to a comprehensive understanding when interpreted together.  
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35 Our study delved into the nuanced experiences of women with HIV through the  
36  
37 lens of CHIWOS, examining psychosocial determinants, clinical aspects, mental health,  
38  
39 sexual and reproductive health outcomes, and healthcare access and quality gaps to  
40  
41 inform policy and programming for women with HIV in Canada. A recurring theme in  
42  
43 the concept maps and summary diagrams was the lack of receipt of comprehensive  
44  
45 women-centred HIV care (3) including lack of discussion of reproductive goals, and  
46  
47 access to care like gender affirmation. This finding suggests providers must improve  
48  
49 knowledge through accessing clinical guidelines related to women with HIV such as the  
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51 Canadian HIV Pregnancy Planning Guidelines, the Guidelines for the Use of  
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3 Antiretroviral Agents in Adults and Adolescents with HIV, the British Columbia  
4  
5 Guidelines for the Care of HIV Positive Pregnant Women & Interventions to Reduce  
6  
7 Perinatal Transmission, and the Sherbourne's Guidelines for Gender-Affirming Primary  
8  
9 Care (25-28). The concept maps also demonstrate the negative effects of low  
10  
11 socioeconomic status and stigma and discrimination on women's self-reported resilience.  
12  
13 This could impact the ability to self-advocate in healthcare settings, further affecting  
14  
15 quality of care received. This finding has important implications to how clinicians and  
16  
17 service providers approach care relationships and the importance of practicing from a  
18  
19 person-centred lens.  
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24 In exploring the intricate layers of women's experiences with HIV, composite  
25  
26 maps 2, 3, and 4 show the profound impact stigma has on the lives of women with HIV.  
27  
28 Societal stigma surrounding HIV not only amplifies the complexities of managing a  
29  
30 chronic health condition, but also significantly contributes to heightened mental and  
31  
32 emotional distress. Within this challenging context, resilience emerges as a pivotal force  
33  
34 in composite maps 1 and 6. The intricate interplay between resilience and stigma reveals  
35  
36 a dynamic process wherein women not only navigate adversity but also actively  
37  
38 contribute to dismantling societal prejudices (29). These composite maps contribute to a  
39  
40 deeper understanding of the complex relationship between stigma, resilience, and  
41  
42 empowerment, which the Wheel of Resilience points to the need for a more supportive  
43  
44 environment for women with HIV.  
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49 The interconnectedness between mental health and experiences of violence in  
50  
51 adulthood further compounds the challenges women with HIV face as seen in composite  
52  
53 maps 1-4. Women with HIV often contend with not only the physiological ramifications  
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3 of the virus but also the psychological distress stemming from social stigma and potential  
4 encounters with violence. The intersectionality of these factors poses a considerable  
5  
6 barrier to accessing mental health support, further exacerbating the mental health  
7  
8 disparities women are experiencing within their communities. Addressing the intricate  
9  
10 relationship between mental health, stigma, and violence is important to fostering a more  
11  
12 comprehensive approach to care for women with HIV, ensuring that interventions are not  
13  
14 only medically sound but also attuned to unique health needs of women.  
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19 Another notable finding was the significance of positive healthy actions in the  
20  
21 health experiences of women with HIV. This theme was evident in several concept maps,  
22  
23 including the Quality of Life concept map which illustrated connections between social  
24  
25 support and reduced HIV-related stigma, and the HIV Care concept map which  
26  
27 demonstrated correlations between peer leadership involvement and increased awareness  
28  
29 of ART prevention benefits. This finding has substantial policy implications, suggesting  
30  
31 that investment in peer leadership and support programs for women with HIV can yield  
32  
33 tangible mental and physical health benefits. Such proactive measures may contribute to  
34  
35 a reduced burden on the greater healthcare system.  
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40 The next steps for policy advocacy are the co-development of a national women-  
41  
42 centred HIV care (30) strategy that ensures equitable access to care including gender  
43  
44 affirmation, and resource creation and education to increase knowledge about the health  
45  
46 care gaps women with HIV experience in Canada. Since the completion of this study, the  
47  
48 field of women-centred HIV care has experienced significant developments, including  
49  
50 the publication of a Women-Centred HIV Care Model informed by CHIWOS findings in  
51  
52 2021 (30), the launch of new women-specific HIV studies such as the British Columbia  
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3 CARMA-CHIWOS (BCC3) study (31), and movement towards a National Action Plan to  
4 advance the sexual and reproductive health and rights of women with HIV in Canada  
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7  
8 (32). Aligned with these recent contributions, the findings from this concept mapping  
9  
10 study underscore persisting unanswered questions and emphasize crucial future research  
11  
12 priorities. One essential research focus that arises from our study is the need to develop  
13  
14 and implement comprehensive women-centred HIV care strategies in clinical settings to  
15  
16 facilitate translation of women's needs to their care providers, thereby influencing  
17  
18 clinical measures of health and well-being. Moreover, our findings, coupled with insights  
19  
20 from the broader literature (3,22,33-38) highlight the diversity among women with HIV,  
21  
22 reflecting the varied nature of their needs. While the Women-Centred HIV Care Model  
23  
24 provides a solid foundation, it is evident that women's priorities and needs vary, often  
25  
26 shaped by other aspects of their identity including race and gender identity. Led by  
27  
28 members of the respective groups and individuals with lived experience, ongoing efforts  
29  
30 are being made to customize and tailor the Women-Centred HIV Care Model for priority  
31  
32 populations, including trans women, African, Caribbean, and Black women, as well as  
33  
34 Indigenous women. Our findings also highlight the need to investigate the intersection of  
35  
36 mental health, stigma, trauma and violence and its impact on the wellbeing of women  
37  
38 with HIV, as well as to develop trauma-informed strategies, approaches and  
39  
40 programming aimed at addressing these intersecting factors. In summary, future research  
41  
42 should concentrate on developing positive and health-oriented actions and programs  
43  
44 tailored to women with HIV, incorporating an intersectional perspective. These efforts  
45  
46 should not only address the unique needs shaped by diverse aspects of identity, but also  
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3 offer leadership and capacity-building opportunities for peer-led initiatives centered  
4  
5 around self-care and wellbeing.  
6

## 7 **Conclusion**

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10 We developed a unifying summary of the health experience of women with HIV  
11  
12 in Canada by applying concept mapping to 60 CHIWOS publications. The produced  
13  
14 visuals can be used to inform policy and programming by providing easy to understand  
15  
16 evidence on gaps related to the social determinants of health including housing, food  
17  
18 security, and income, in addition to structural barriers such as multiple areas of  
19  
20 discrimination. Importantly, these visuals promote strength-based approaches to women  
21  
22 with HIV's health and wellbeing. The results of this study should guide future research  
23  
24 and care priorities for women with HIV in Canada, placing a specific emphasis on  
25  
26 trauma-informed, peer-led positive healthy actions accessible to women in all their  
27  
28 diversity. This includes initiatives aimed at enhancing women-centred HIV care and self-  
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30 care to comprehensively improve the holistic wellbeing of women with HIV.  
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1  
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4 study. The authors would also like to thank LJ from The Public Studio for his  
5  
6 collaboration in creating the two summary diagrams.  
7  
8

### 9 **Contributions**

10  
11  
12 AY, PM, MK and ML contributed to the study conception and design. AY, PM, MK, and  
13  
14 BG contributed to the preparation, participant recruitment, and publication screening  
15  
16 process. AY, PM, MK, and ML participated in the development of concept maps and  
17  
18 summary diagrams. PM, JK, and ML wrote the first draft of the manuscript. VN, RG, PF,  
19  
20 YP, NO, BG, BB, SS, MN, AF, BG, CC, KW, MS, AL, CL, AP, AK, and ML provided  
21  
22 feedback and edits on all the visuals and versions of the manuscripts. All authors have  
23  
24 read and agreed to the published version of the manuscript.  
25  
26

27  
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33  
34 Trials Network under Grant CTN 262 at the time of this study.  
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37  
38 **Competing Interests:** None declared.  
39

40 **Patient Consent:** Obtained  
41

42 **Patient and public involvement:** Patients and/or the public were involved in the design,  
43  
44 conduct, or dissemination plans of this research. Refer to the Methods for further details.  
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47 **Data Availability Statement:** No additional data available.  
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3 **Ethics Approval:** The study was assessed by the research ethics board at Women's  
4  
5 College Hospital to not require ethical approval by a human research ethics committee  
6  
7 because the Ethical Principles for Medical Research Involving Human Subjects did not  
8  
9 apply. Refer to the Methods for further details.  
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5 Figure 1 – Applying the Eligibility Criteria to CHIWOS Publications  
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7 Figure 2 - Example of an individual concept map from one publication (Access to Care,  
8 Kronfil et al., 2017)  
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10 Figure 3 - CHIWOS Summary Diagram – Honouring the Experiences of Women with  
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13 Figure 4 - CHIWOS Summary Diagram – Honouring the Experiences of Trans Women  
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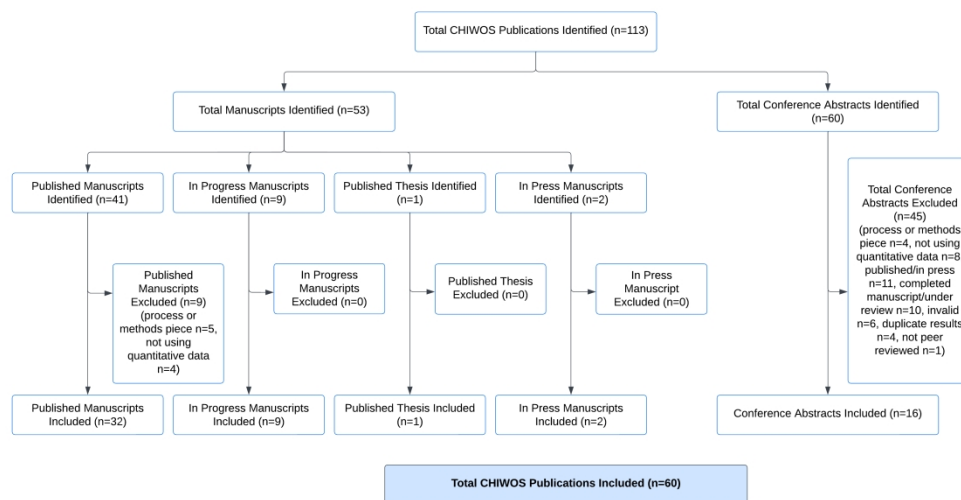


Figure 1: Applying the Eligibility Criteria to CHIWOS Publications

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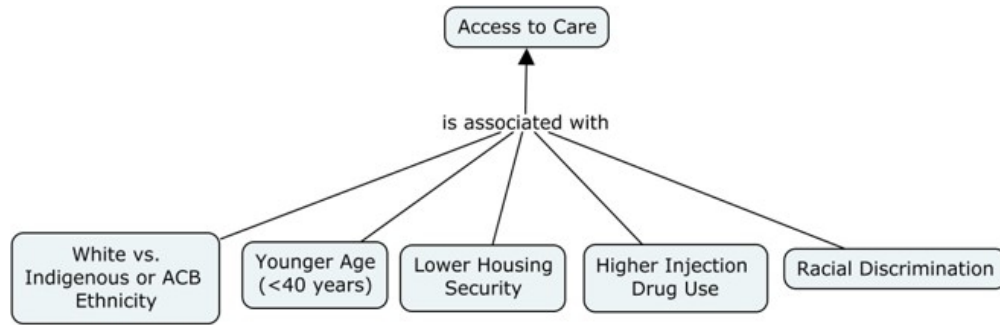


Figure 2: Example of an individual concept map from one publication (Access to Care, Kronfil et al., 2017)

173x55mm (96 x 96 DPI)



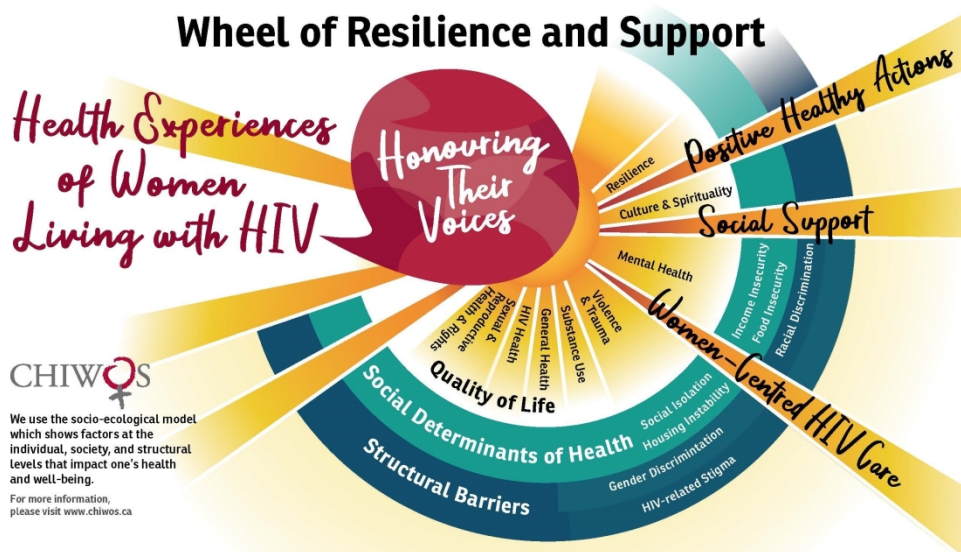


Figure 3: CHIWOS Summary Diagram – Honouring the Experiences of Women with HIV

338x190mm (200 x 200 DPI)

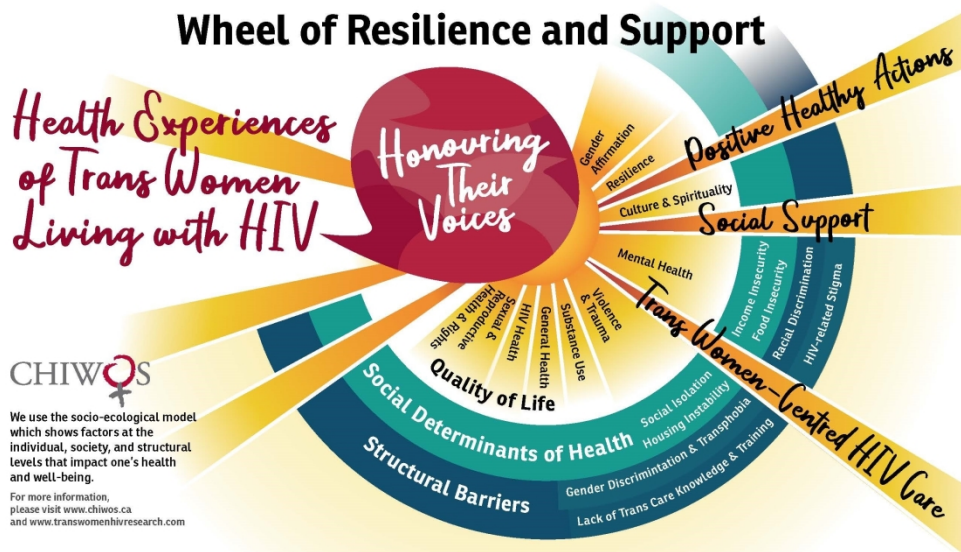


Figure 4: CHIWOS Summary Diagram – Honouring the Experiences of Trans Women Living with HIV

338x190mm (200 x 200 DPI)

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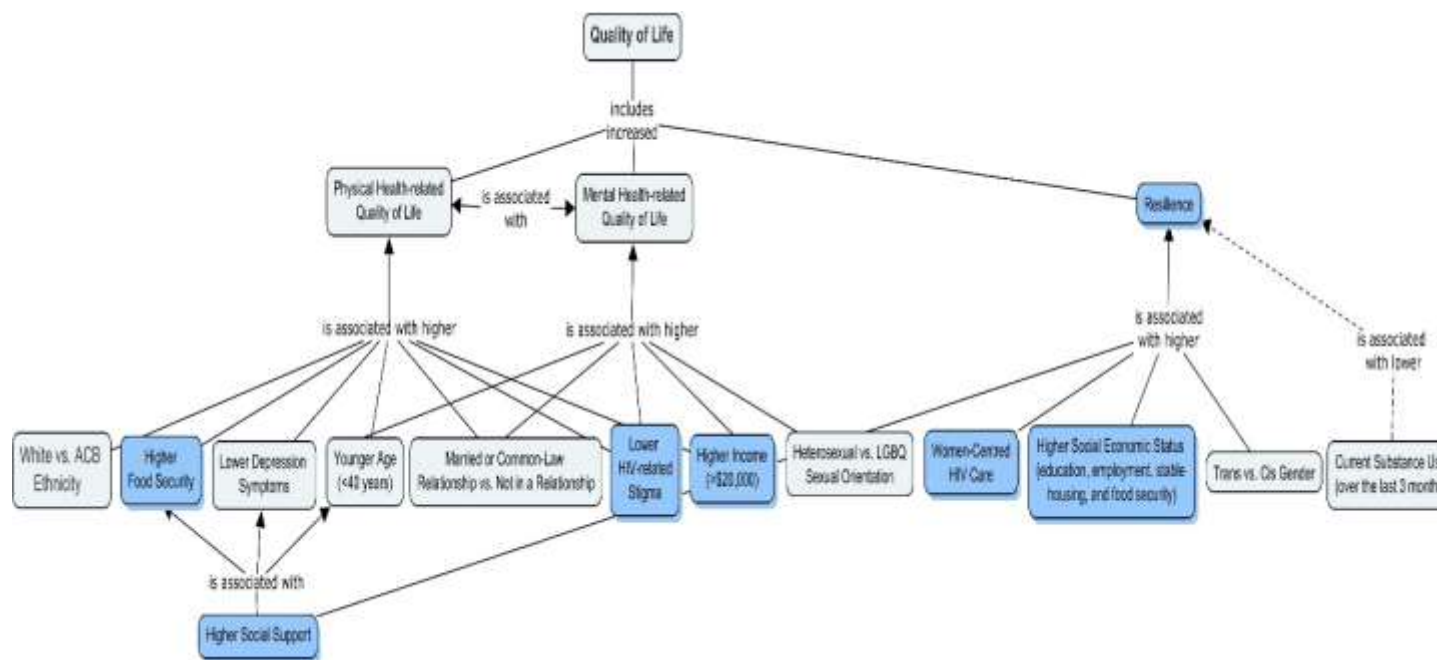
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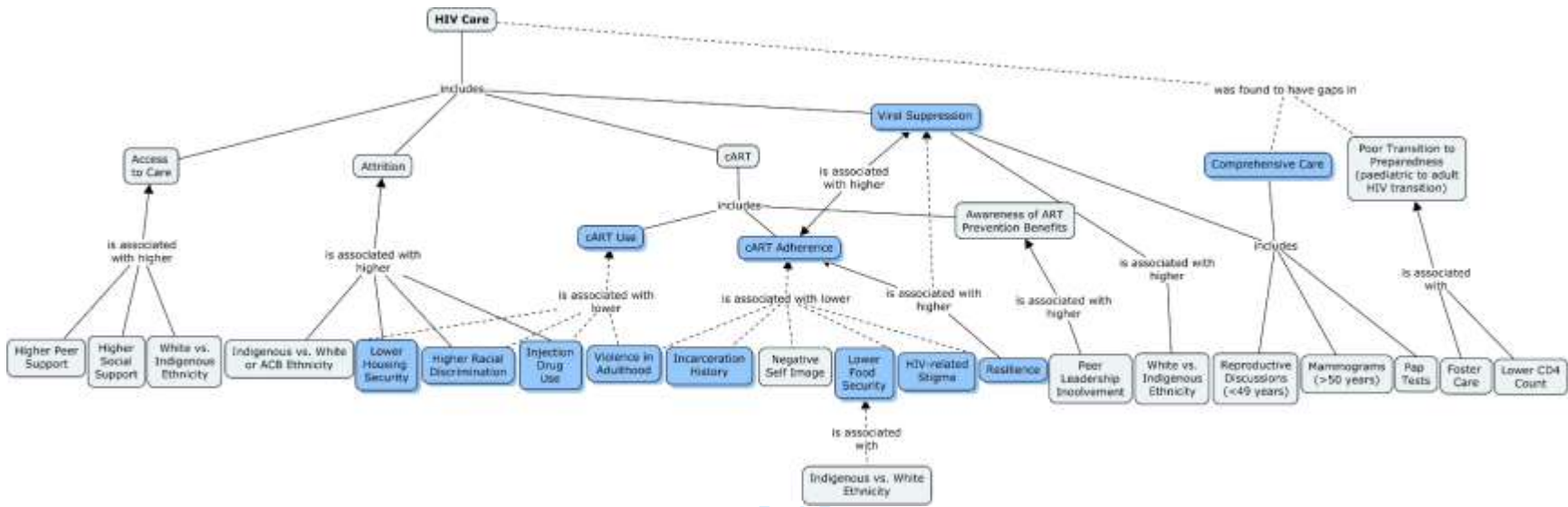


Supplementary Figure 1: Quality of Life Concept Map



Our definition of Quality of Life (QOL) extends beyond one’s physical and mental health status. It is expanded to also include QOL’s relationship with resilience and overall wellbeing. QOL was measured using the SF-12 scale.

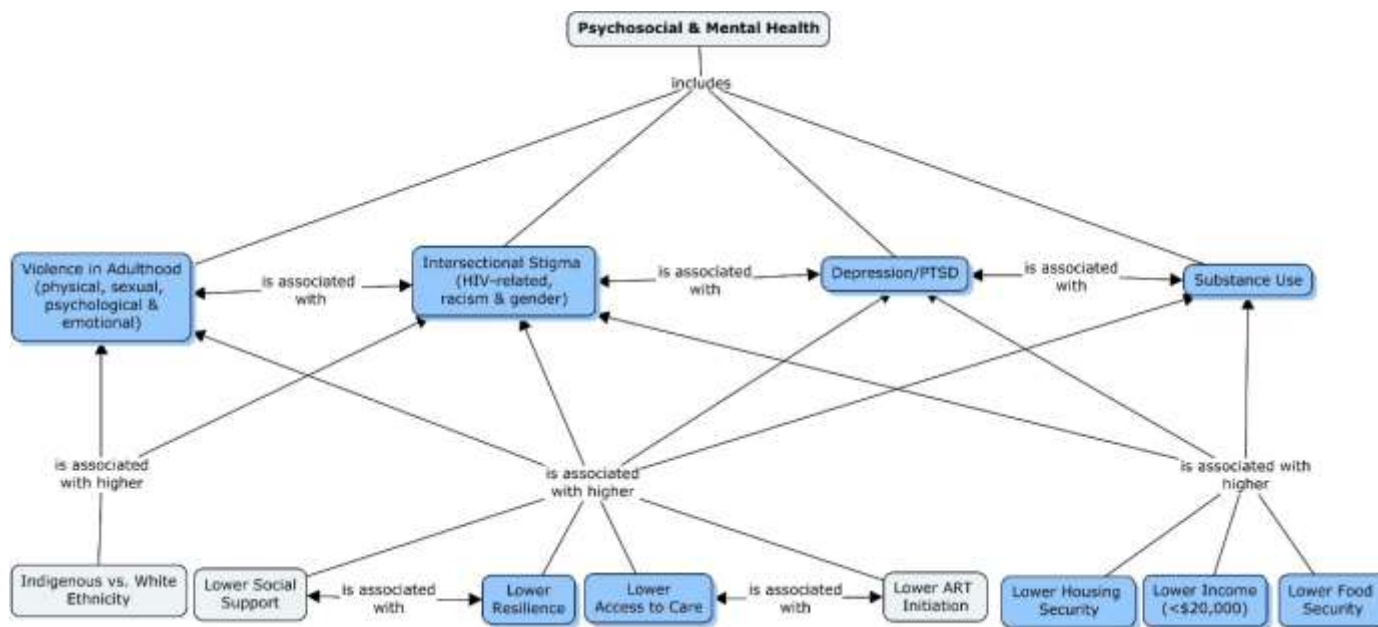
Supplementary Figure 2: HIV Care Concept Map



Attrition refers to reduction in the % at each stage of the HIV care cascade. These stages are: 1) access to care, 2) cART use, 3) cART adherence, and 4) viral suppression.

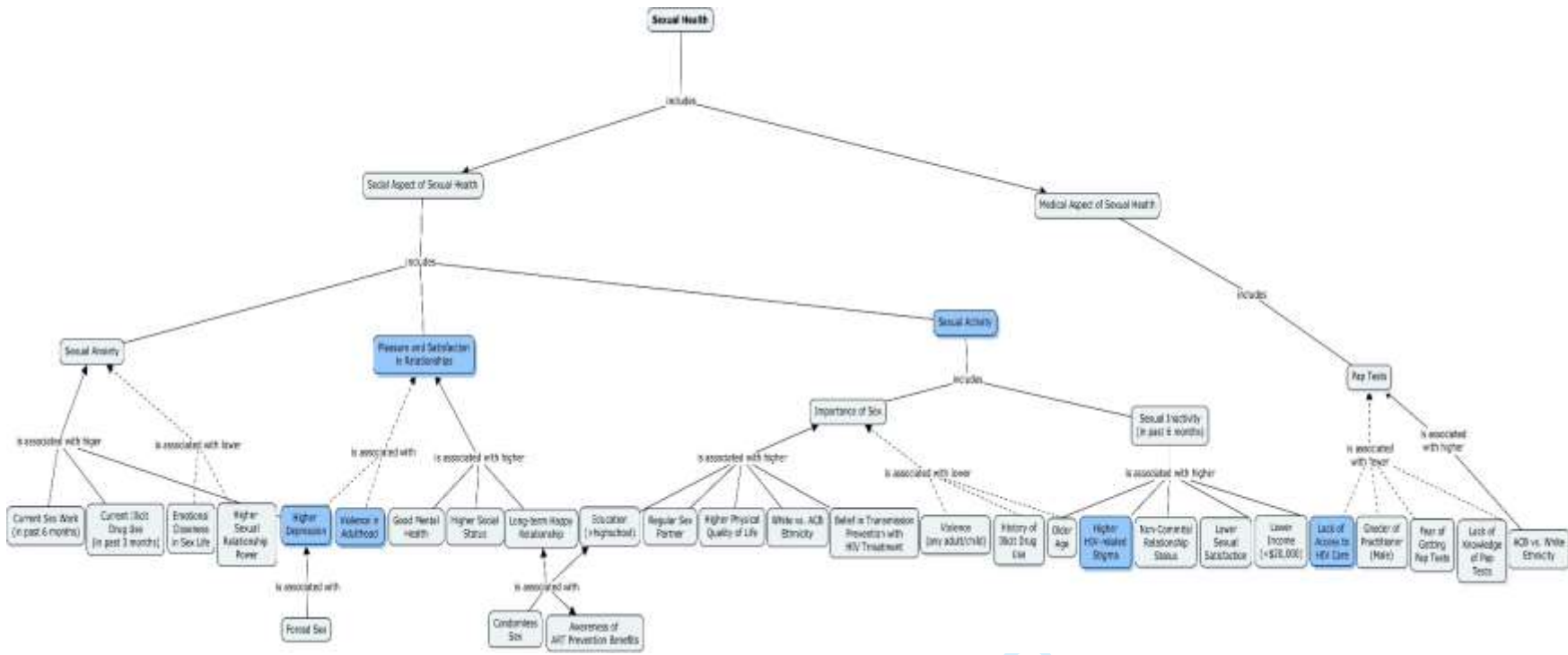
Comprehensive care is defined by four indicators: Pap test, viral load suppression, reproductive discussions, and mammograms.

Supplementary Figure 3: Psychosocial and Mental Health Concept Map



Intersectional stigma, violence, depression/PTSD, and substance use are associated with each other. Also, access to care was measured using the Barriers to Access to Care 12-item scale.

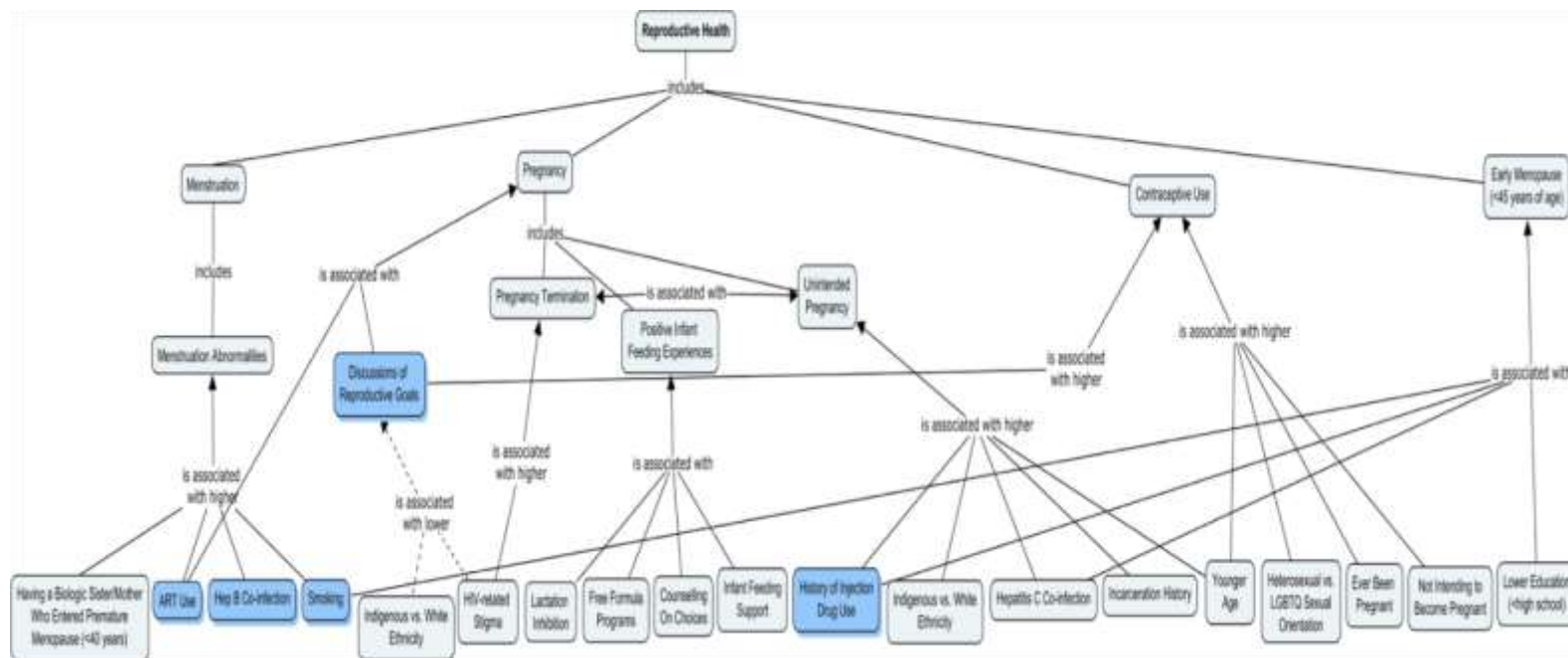
Supplementary Figure 4: Sexual Health Concept Map



There are various medical aspects of sexual health, including the experiences and management of sexually transmitted infections; however, CHIWOS has not yet analyzed data on them.

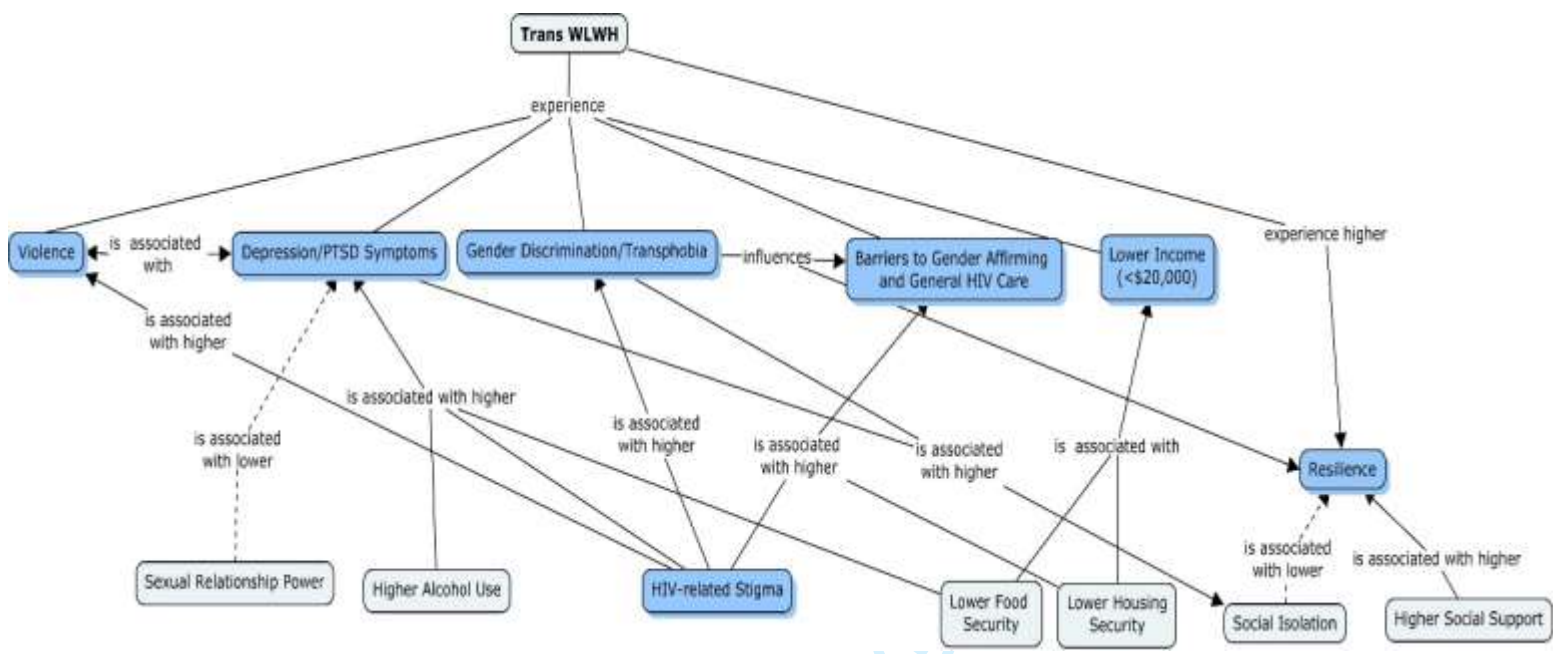
Sexual activity was defined as consensual sex (oral or penetrative) in the past six months based on the questionnaire used; but it is understood to represent much more including sexual desire, sexual needs, sexual being, and more.

Supplementary Figure 5: Reproductive Health Concept Map



CHIWOS findings showed a narrow range of contraceptive methods used.

Supplementary Figure 6: Trans WLWHIV Concept Map



Social isolation is the absence of social and economic supports (i.e., lower income, housing, and food services) which are barriers to ongoing engagement in HIV care. These variables are in comparison to cis-gender women.

# BMJ Open

## Experiences and resultant care gaps among women with HIV in Canada: concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) findings

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	Care, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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Manuscripts





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## Experiences and resultant care gaps among women with HIV in Canada: concept mapping the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) findings

### Abstract

**Objectives:** The community-based, longitudinal, Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) explored the experiences of women with HIV in Canada over the past decade. CHIWOS' high impact publications document significant gaps in the provision of health care to women with HIV. We used concept mapping to analyse and present a summary of CHIWOS findings on women's experiences navigating these gaps.

**Design:** Concept mapping procedures were performed in two steps between June 2019 and March 2021. First, two reviewers (AY and PM) independently reviewed CHIWOS manuscripts and conference abstracts written before 1 August 2019 to identify main themes and generate individual concept maps. Next, the preliminary results were presented to national experts, including women with HIV, to consolidate findings into visuals summarizing the experiences and care gaps of women with HIV in CHIWOS.

**Setting:** British Columbia, Ontario and Quebec, Canada.

**Participants:** A total of 18 individual CHIWOS team members participated in this study including six lead investigators of CHIWOS and 12 community researchers.

**Results:** Overall, a total of 60 peer-reviewed manuscripts and conference abstracts met the inclusion criteria. Using concept mapping, themes were generated and structured through online meetings. In total, six composite concept maps were co-developed: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women's health. Two summary diagrams were created encompassing the concept

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3 map themes, one for all women and one specific to trans women with HIV. Through our  
4  
5 analysis, resilience, social support, positive healthy actions, and women-centred HIV care  
6  
7 were highlighted as strengths leading to well-being for women with HIV.  
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10 **Conclusions:** Concept mapping resulted in a composite summary of 60 peer-reviewed  
11  
12 CHIWOS publications. This activity allows for priority setting to optimize care and well-  
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14 being for women with HIV.  
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19 **Keywords:** HIV, women's health, healthcare systems, care gaps, concept mapping  
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### 23 24 **Strengths and limitations of this study**

- 25  
26 ● The study comprehensively summarizes the health experiences of women with  
27  
28 HIV enrolled in the Canadian HIV Women's Sexual and Reproductive Health  
29  
30 Cohort Study (CHIWOS) and identifies potential gaps in their care.  
31  
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- 33 ● A diverse group of women and HIV experts across Canada took part in this study  
34  
35 to provide feedback on the concept maps which used results from 60 peer-  
36  
37 reviewed publications by, with and for women with HIV.  
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- 40 ● Between June 2019 and March 2021, the process of concept mapping and  
41  
42 reviewing visualizations with key informants occurred, with a cut-off date of  
43  
44 August 1, 2019 for new publications; however, manuscripts under review or  
45  
46 nearing publication were considered and all have since been published.  
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- 49 ● Although efforts were made to engage team members from all provinces included  
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51 in the CHIWOS study, only community researchers from Ontario and British  
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3 Columbia agreed to take part in this study, though academic researchers from  
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5 Quebec participated.  
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## 10 INTRODUCTION

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12 Recent studies have found that women with HIV experience unique health and social  
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14 needs that differ from those of men with HIV and limit their access to treatment and care  
15  
16 services (1-3). The historical lack of research focusing on the realities of women with  
17  
18 HIV may be detrimental to their health (4,5). These circumstances led to the development  
19  
20 and implementation of the Canadian HIV Women's Sexual and Reproductive Health  
21  
22 Cohort Study (CHIWOS) – the largest community-based study in Canada exploring the  
23  
24 experiences and priorities of a diverse, national cohort of women with HIV in British  
25  
26 Columbia (BC), Ontario (ON), and Quebec (QC) from 2013-2018.  
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30  
31 CHIWOS was initiated in 2011 through a qualitative phase, which informed the  
32  
33 creation of an in-depth survey (1,2). The study's objectives were to examine women's  
34  
35 access to women-centred HIV care and the impact of corresponding usage patterns on  
36  
37 health outcomes (2). CHIWOS was guided by principles of equitable involvement of  
38  
39 those affected *by* the research *in* the research process by establishing community-  
40  
41 academic partnerships and shared decision-making throughout the study (6,7). This  
42  
43 research approach, reflecting community-based research (CBR) values, was enacted in  
44  
45 part through the involvement of women with HIV as trained community researchers to  
46  
47 conduct research activities in each stage of the project (2,8,9). CHIWOS was created by,  
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49 with, and for women with HIV in collaboration with academic researchers, clinicians,  
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51 and community partners to investigate women's mental, sexual and reproductive health  
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3 care priorities, and need for a women-centred HIV care model (1,2,10). Cohort data  
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5 collection was launched in 2013 and collected at three time points, 18 months apart, from  
6  
7 August 2013 to September 2018. A complete description of CHIWOS can be found at  
8  
9 [www.chiwos.ca](http://www.chiwos.ca). As of publication acceptance, CHIWOS remains the largest longitudinal  
10  
11 study of women with HIV in Canada, successfully enrolling a diverse cohort of 1,422  
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13 women with HIV (356 from BC [25%], 713 from ON [50%], and 353 from QC [25%])  
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15 (1,2).  
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19 As of August 2019, a total of 113 publications (53 manuscripts and 60 conference  
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21 abstracts) had been written using CHIWOS data. This academic content explores dozens  
22  
23 of specific topics related to the experiences of women with HIV, including psychosocial  
24  
25 determinants, clinical, mental, sexual, and reproductive health outcomes, as well as  
26  
27 access to, and quality of healthcare that characterize women's health gaps and needs and  
28  
29 that can be used to inform programming and policy in Canada. In an effort to better  
30  
31 understand the main topics and gaps of CHIWOS manuscripts and conference abstracts,  
32  
33 this study applied Novak and Gowin's (1984) concept mapping methodology (11). The  
34  
35 goal of this methodology was to visualize concepts of CHIWOS findings in a hierarchical  
36  
37 fashion, with the most inclusive and general concepts at the top of the map, and specific  
38  
39 concepts arranged hierarchically below to represent the inter-related relationships in each  
40  
41 publication included. We sought to apply these findings towards the creation of a  
42  
43 summary diagram to summarize the health experiences and gaps of women with HIV  
44  
45 enrolled in CHIWOS. An added benefit of using concept mapping in this study is that the  
46  
47 simplistic visualizations allowed for increased accessibility of the CHIWOS findings to  
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49 those outside of academia, including some community members and knowledge users,  
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3 which enabled shared decision-making to inform the final product. Our goal was to use  
4 these findings to characterize women with HIV's healthcare needs and gaps to inform  
5 policy and programming in Canada.  
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## 9 10 **METHODS**

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12 Concept mapping is a graphical methodology used to organize and present knowledge.  
13  
14 Since its conception by Novak (1974) (12), it has been adapted in qualitative research to  
15 present findings and analyze themes (13,14). This methodology was chosen to illustrate  
16 the key themes from the CHIWOS publications, including both manuscripts and  
17 conference abstracts, and their relation to each other in order to demonstrate the  
18 experiences and related gaps in care women with HIV face in Canada. We used a social-  
19 ecological perspective to understand the interplay between multi-level factors impacting  
20 women with HIV, their community, and society (15-17).  
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31 For this study, the concept mapping process from Novak (1998) (18) was used  
32 and encompassed five steps:  
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### 36 **Step 1: Conduct a thematic analysis on CHIWOS publications and summarize key** 37 **findings** 38 39

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41 All CHIWOS publications (including manuscripts and conference abstracts) published,  
42 under review, or near publication submission before 1 August 2019 were examined  
43 alongside inclusion criteria developed by the core concept team (including AY, MK, ML,  
44 and PM). To be included for review, manuscripts were to 1) include national quantitative  
45 CHIWOS questionnaire data, and 2) be published, under review or near submission in a  
46 peer-reviewed journal (manuscripts) or be presented at a HIV-related conference  
47 (abstracts) by the exclusion date.  
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Manuscripts that did not use quantitative CHIWOS data or were process or methods pieces were excluded. For conference abstracts, those which had been published or submitted as manuscripts, showed duplicate results to other abstracts, or were not peer-reviewed prior to conference presentation were excluded. Figure 1 shows the selection process. The inclusion and exclusion criteria were designed to ensure a comprehensive and representative analysis, encompassing all eligible manuscripts or conference abstracts, thereby mitigating the potential for bias or skew in the publication list. A total of 113 CHIWOS publications (including manuscripts and conference abstracts) were reviewed, of which 53 were excluded. This resulted in 60 eligible publications that met the inclusion criteria (summarized in Table 1). Eligible publications were grouped together by their overarching theme (discussed further in step 3).

**Table 1.** Summary of included CHIWOS publications

Composite Concept Map Theme	Manuscripts (n=44)	Conference Abstracts (n=16)
Quality of life	n=4 (a) <a href="#">Logie, Wang et al. 2018</a> <a href="#">Carter, Loutfy et al. 2018</a> <a href="#">Kteily-Hawa, Andany et al. 2019</a> <a href="#">Kteily-Hawa, Warren et al. 2019</a>	
HIV care	n=8 <a href="#">Kennedy, Mellor et al. 2020</a> <a href="#">Kerkerian, Kestler et al. 2018</a> (a) <a href="#">Kronfli, Lacombe-Duncan et al. 2017</a> (b) <a href="#">Kronfli, Lacombe-Duncan et al. 2017</a> (b) <a href="#">Logie, Wang et al. 2018</a> <a href="#">Loutfy, de Pokomandy et al. 2017</a> <a href="#">O'Brien, Godard-Sebillotte et al. 2019</a> (a) <a href="#">Shokoohi, Bauer et al. 2019</a>	n=4 Conway, Gormley et al. 2019 Kaida, Conway et al. 2019 Loutfy, de Pokomandy et al. 2015 Puskas, Pick et al. 2018
Psychosocial & mental health	n=14	n=5

	<a href="#">Carter, Roth et al. 2018</a> <a href="#">Churchill. 2018</a> <a href="#">Gormley, Nicholson al. 2021</a> <a href="#">Heer, Kaida et al. 2022</a> <a href="#">Jaworsky, Logie et al. 2018</a> (a) <a href="#">Logie, Lacombe-Duncan et al. 2018</a> <a href="#">Logie, Marcus et al. 2019</a> (c) <a href="#">Logie, Wang et al. 2018</a> <a href="#">Logie, Williams et al. 2019</a> <a href="#">Patterson, Nicholson et al. 2020</a> <a href="#">Shokoohi, Bauer et al. 2018</a> (b) <a href="#">Shokoohi, Bauer, et al. 2019</a> (c) <a href="#">Shokoohi, Bauer et al. 2019</a> <a href="#">Wagner, Jaworsky et al. 2018</a>	Kaida, Nicholson et al. 2019 (a) Logie, Wang et al. 2019 (b) Logie, Wang et al. 2019 Parry, Lee et al. 2019 Underhill, Wu et al. 2018
Sexual health	n=8	n=2
	(a) <a href="#">Carter, Greene et al. 2018</a> (b) <a href="#">Carter, Greene, et al. 2018</a> <a href="#">Carter, Greene et al. 2019</a> <a href="#">Carter, Patterson et al. 2020</a> <a href="#">de Pokomandy, Burchell et al. 2019</a> <a href="#">Kaida, Carter et al. 2015</a> <a href="#">Logie, Kaida et al. 2020</a> <a href="#">Patterson, Carter et al. 2017</a>	Salters, Loutfy et al. 2015 Underhill, Kennedy et al. 2017
Reproductive health	n=6	n=4
	<a href="#">Andany, Kaida et al. 2020</a> <a href="#">Fortin-Hughes, Proulx-Boucher et al. 2019</a> <a href="#">Kaida, Patterson et al. 2017</a> <a href="#">Salters, Loutfy et al. 2017</a> <a href="#">Skeritt L, de Pokomandy et al. 2021</a> <a href="#">Valiaveetil, Loutfy et al. 2019</a>	Boucoiran, Kaida et al. 2019 Kaida, Gormley et al. 2019 Kaida, Money et al. 2017 Siou, Salters et al. 2016
Trans women with HIV	n=4	n=1
	<a href="#">Lacombe-Duncan, Bauer et al. 2019</a> <a href="#">Lacombe-Duncan, Newman et al. 2017</a> <a href="#">Lacombe-Duncan, Warren et al. 2021</a> (b) <a href="#">Logie, Lacombe-Duncan et al. 2018</a>	Lacombe-Duncan, Persad et al. 2017

See Supplementary Material for full citations.



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3 From the 60 included manuscripts and conference abstracts, we began by  
4  
5 identifying the major findings of each that answered the guiding question: what  
6  
7 characterizes the healthcare gaps and needs of CHIWOS participants? We examined  
8  
9 publications to identify themes related to gaps in care, as well as explicit findings related  
10  
11 to healthcare access and quality. We then used the coding step of a thematic analysis (19)  
12  
13 to code the findings into their simplest form (e.g., lower food security is associated with  
14  
15 increased substance use). As a last step, we listed the concepts and linking words within  
16  
17 each code (e.g., concepts = lower food security, substance use; linking words = is  
18  
19 associated with) (19). This process was repeated for each manuscript and conference  
20  
21 abstract. In our efforts to mitigate theme overrepresentation, we opted to include an  
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23 abstract only when a corresponding manuscript was not available. However, given the  
24  
25 inherent intersectionality of the data, there may be instances where subsets of the data  
26  
27 were presented in multiple publications. A thorough exploration of such cases is provided  
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29 in the discussion section for clarity and transparency.  
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## 36 **Step 2: Individual concept mapping of CHIWOS manuscripts and abstracts**

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38 The concepts and linking words from Step 1 were used to guide the design of 60  
39  
40 individual concept maps, each visually summarizing the key findings of one manuscript  
41  
42 or conference abstract. Figure 2 is an example of one of the individual concept maps we  
43  
44 created from the CHIWOS findings.  
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48 Within each map, concepts were listed in hierarchical order with the most  
49  
50 overarching general concepts at the top and the most specific concepts at the bottom (11).  
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52 Using an online software, CMAPTools (20), concepts were designated by boxes and lines  
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54 were drawn from one concept to another with the linking words placed in between. We  
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3 adapted the concept map process by adding in extra features that better visually represent  
4 the CHIWOS findings. For example, arrowheads pointed towards outcomes of CHIWOS  
5 findings. Bi-directional arrows were used when a relationship was present between two  
6 outcomes. Solid lines represented a positive association between concepts while dotted  
7 lines represented a negative association between concepts. Concepts that recurred in two  
8 or more individual concept maps were considered critical findings and were designated  
9 by a blue shaded concept box.

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AY and PM independently reviewed each concept map to ensure all major findings were represented and summarized into the visual. If there was a discrepancy, a third reviewer (ML) was consulted to make the final decision.

### **Step 3: Compilation of individual concept maps into composite concept maps**

AY, PM, and ML grouped the maps with main concepts and similar themes together. Six major themes were identified: quality of life, HIV care, psychosocial and mental health, sexual health, reproductive health, and trans women with HIV.

The individual concept maps that fell under each major theme were compiled together to create a composite concept map. AY and PM drew cross-links between concepts that had relationships but were on different domains of the composite concept map (14). This process was repeated for each theme and six composite concept maps were developed.

### **Step 4: Internal development team review and brainstorming of overarching visualization**

An internal team (including AY, MK, ML, and PM) meeting was held in August 2019 to review all six composite concept maps. The goal was to ensure all key findings were

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2  
3 represented on the maps with good readability. The guiding question was referred to  
4  
5 when deciding to remove or add concepts to the map. The team then brainstormed ideas  
6  
7 to design a compilation visual representing the findings of the six composite maps that  
8  
9 answered our guiding research question. A preliminary sketch was formed which is now  
10  
11 referred to as the summary diagram.  
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### 15 **Step 5: External expert team review and validation**

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17 The first author of each included CHIWOS manuscript and conference abstract (herein  
18  
19 referred to as lead investigators), and all CHIWOS community researchers were  
20  
21 identified as potential key participants in this study and were approached for recruitment  
22  
23 from October 2019 to November 2020. Over 30 CHIWOS academic and community  
24  
25 team members from all three provinces were invited to participate in the study by email,  
26  
27 of which 18 agreed to participate. A total of 29 meetings were held with groups of  
28  
29 participants and took place both in-person and virtually.  
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34 For orientation, introductory slides explaining the concept mapping methodology  
35  
36 and its application to CHIWOS findings were shown to the group. Each of the six  
37  
38 composite concept maps were then presented. Lead investigators were asked to ensure  
39  
40 that all major CHIWOS findings were accurate and present, and community researchers  
41  
42 were asked to ensure that the experiences of women with HIV were accurately  
43  
44 represented. All participants were asked to provide input on the readability, clarity, and  
45  
46 inclusivity of language. Next, the summary diagram was presented, and participants were  
47  
48 asked to ensure that all key components from the composite concept maps were included  
49  
50 in the summary diagram, in addition to providing feedback on design features including  
51  
52 colour, layout, and display of content. All participant feedback was documented and the  
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3 feedback between different focus groups were compared. All suggestions and changes  
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5 were reviewed by AY and PM through revisiting the manuscript and abstracts and  
6  
7 addressing the guiding research question. Updated composite theme maps and the  
8  
9 summary diagrams were presented at a follow-up meeting and consensus was reached by  
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11 discussion.  
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### 14 **Ethics approval**

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16 The study was assessed by the research ethics board at Women's College Hospital to not  
17  
18 require ethical approval by a human research ethics committee because the Ethical  
19  
20 Principles for Medical Research Involving Human Subjects did not apply. Instead,  
21  
22 participants, all of whom had been previously engaged as CHIWOS research team  
23  
24 members participated as research consultants to the concept process on a volunteer basis.  
25  
26 We obtained informed consent from all participants in CHIWOS.  
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### 30 **Patient and public involvement**

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32 Evidently, women with HIV (community researchers; those previously involved in the  
33  
34 CHIWOS project) were involved in the study. Their invaluable insights significantly  
35  
36 contributed to the thematic analysis and individual concept mapping, offering a nuanced  
37  
38 perspective on healthcare gaps and needs. Additionally, their active participation in  
39  
40 validating composite concept maps and the summary diagram guaranteed precision and  
41  
42 inclusivity in the representation of findings. In recognition of their contributions, all  
43  
44 community members involved were appropriately compensated for their time and  
45  
46 expertise.  
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## 51 **RESULTS**

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3 A total of 18 individuals participated in the design and review of the concept maps,  
4 including six academic investigators (BC: n=1; ON: n=3; QC: n=2), and 12 community  
5 researchers (BC: n=5; ON: n=7). All participants identified as cis or trans women.  
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7

### 10 **Composite concept maps**

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12 Overall, six composite maps were created (see Supplementary Figures 1-6).  
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14  
15 We developed composite concept map 1 (see Supplementary Figure 1) from four  
16 manuscripts focused on the topic of quality of life. Notable findings in this map include  
17 bi-directional association of physical and mental health quality of life, and the association  
18 of experiences of women-centred HIV care with higher resilience and in turn higher  
19 quality of life. This map illustrates the influence socioeconomic status, experiences of  
20 stigma, sexual orientation, substance use, social support, and relationship status have on  
21 mental and physical health-related quality of life.  
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31 From eight manuscripts and four conference abstracts, composite concept map 2  
32 (see Supplementary Figure 2) was created to illustrate findings related to HIV care. This  
33 map demonstrates associations between several aspects of HIV care including viral  
34 suppression, use of combination antiretroviral therapy (cART), care access and attrition.  
35 Notable findings include the effect having social and peer support have on increasing  
36 access to HIV care and the effect of racial discrimination on care attrition. Experiencing  
37 violence in adulthood was found to reduce cART use and adherence, leading to reduced  
38 viral suppression. On the other hand, peer leadership involvement was associated with  
39 higher awareness of cART prevention benefits.  
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52 Composite concept map 3 (see Supplementary Figure 3) demonstrates the  
53 connections between various facets of psychosocial and mental health and represents data  
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3 from 14 manuscripts and five abstracts. Indigenous heritage was associated with  
4  
5 experiencing higher violence in adulthood as well as lower housing security and income.  
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7 Lower food security was associated with higher substance use. This map emphasizes the  
8  
9 negative impact of intersectional stigma on all aspects of mental health, which are  
10  
11 associated with clinical measures like a lack of cART initiation.  
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13

14  
15 The most complex of the six visuals is composite concept map 4 (see  
16  
17 Supplementary Figure 4) which explores sexual health experiences of women enrolled in  
18  
19 CHIWOS. This map represented data from eight manuscripts and two abstracts. Its  
20  
21 findings were organized into social and medical aspects of sexual health sub-categories.  
22  
23 A main finding was the association of higher depression and experienced violence in  
24  
25 adulthood with lower pleasure and satisfaction in relationships. Higher HIV-related  
26  
27 stigma was also associated with higher sexual inactivity in the past six months, which  
28  
29 was a recurring theme in the included publications.  
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34 The fifth composite concept map (see Supplementary Figure 5) showed CHIWOS  
35  
36 findings related to reproductive health. The production of this map as separate from  
37  
38 sexual health was intentional to illustrate that for many women, sexual health goes  
39  
40 beyond reproductive health desires or lack thereof. This map drew on data from six  
41  
42 manuscripts and four abstracts, and includes sub-categories of menstruation, pregnancy,  
43  
44 contraceptive use, and early menopause. Findings showed low use of a narrow range of  
45  
46 contraceptive methods, with sexual orientation, previous pregnancies, and age  
47  
48 influencing contraceptive choice. Service provider counselling on choices for infant  
49  
50 feeding practices, support and free formula programs were associated with positive infant  
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52 feeding experiences for women.  
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3 The final map titled Trans Women Concept Map (see Supplementary Figure 6)  
4 included topics from all five of the other composite concept maps but from the exclusive  
5 perspective of trans women in CHIWOS, with data drawn from four manuscripts and one  
6 abstract that solely analysed trans women's data. This map shows trans women's  
7 experiences of gender discrimination and transphobia, which influence barriers to gender  
8 affirming and general HIV care, with HIV-related stigma playing a significant role in this  
9 association. Higher sexual relationship power was associated with lower depression and  
10 post-traumatic stress disorder symptoms. Higher social support was associated with  
11 resilience, which trans women experienced higher levels of than cis women in CHIWOS.  
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### 23 **Summary diagrams**

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25 From the six composite concept maps, two summary diagrams were created (see Figures  
26 3 and 4), one for all women and one for trans women specifically. These diagrams  
27 provide a summary of the key insights, barriers, and supports that affect the health and  
28 well-being of women with HIV involved in CHIWOS. Through actively participating in  
29 the arts-based design process of the two summary diagrams, community researchers  
30 played a vital role in shaping both the overall themes presented and the final visual of the  
31 diagrams. They insisted on grounding the diagrams in the stories and experiences of  
32 CHIWOS participants, highlighting the importance of making them accessible,  
33 empowering, holistic, authentic, and inclusive - these specific terms were consistently  
34 used by community researchers during our collaborative meetings as we worked together  
35 on developing the diagrams. The meaningful engagement of community researchers (who  
36 collected the CHIWOS data) ensured women with HIV were represented and involved in  
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3 shared decision-making between community and academic team members in the creation  
4  
5 of these diagrams.  
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8 We utilized a socio-ecologic model in developing the summary diagrams to show  
9  
10 how the individual, societal, and structural factors present in the concept maps intersect  
11  
12 to affect women's health and well-being (11-13). To visually represent this intersection,  
13  
14 the diagram was created in the shape of concentric circles. At the centre of both visuals is  
15  
16 a speaking bubble highlighting the stories that women who participated in CHIWOS  
17  
18 shared and was named by the community researchers: "Honouring Their Voices." The  
19  
20 inner circle of both figures highlights the aspects that are important to women's quality of  
21  
22 life: HIV health, general health including physical, health, sexual and reproductive  
23  
24 health, mental health, violence and trauma, substance use, culture and spirituality, and  
25  
26 resilience. Surrounding quality of life are social factors that combine to affect the health  
27  
28 of individuals and their communities, such as housing stability, food security, income,  
29  
30 and social isolation. The outer circle consists of the structural factors that affect health  
31  
32 including HIV-related stigma, and gender and racial discrimination. Intersecting these  
33  
34 layers of the women's health experiences are the important ways women are addressing  
35  
36 barriers in their lives, including through social support, accessing, or calling to action the  
37  
38 need for women-centred HIV care, and positive healthy actions.  
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45 Through consultations with a trans women advocate and CHIWOS team member,  
46  
47 the second summary diagram (see Figure 4) was created to reflect the most important and  
48  
49 recurring findings of the concept mapping exercise as they relate to the experiences of  
50  
51 trans women with HIV involved in CHIWOS. The main difference from Figure 3 is the  
52  
53 addition of gender affirmation in the inner circle in reference to trans women's  
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3 experiences. Community researchers define gender affirmation whereby an individual  
4 receives the affirmation they desire with respect to their gender identity and expression  
5  
6 from those around them, including social recognition and/or medical access to care such  
7  
8 as hormone therapy and gender-affirming surgeries.  
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12 Together, the composite concept maps show that there are both commonalities  
13  
14 and differences in the experiences of women with HIV; however, resilience was present  
15  
16 among all CHIWOS participants.  
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20 Through facilitated discussions with The Public Studio, an activist design studio  
21  
22 in Toronto (<https://thepublicstudio.ca/>), we identified that community partners wanted: 1)  
23  
24 a sun to be a theme of the visuals that radiates energetically from the centre of the  
25  
26 diagram and 2) a strength-based title such as the “Wheel of Resilience and Support.” It  
27  
28 was important to the community partners that the visuals served as an invitation to  
29  
30 translate the stories of CHIWOS participants into action.  
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### 33 **DISCUSSION**

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35 The six composite concept maps and two summary diagrams show a decade of work  
36  
37 done by the CHIWOS team, providing a dynamic mosaic of information representative of  
38  
39 the intricacies of women’s experiences (11-13). The co-creation of concept maps, distinct  
40  
41 from traditional systematic reviews, offers an innovative and valuable approach to  
42  
43 understanding the health experiences of women with HIV, providing novel insights that  
44  
45 extend beyond individual publications for a more comprehensive and nuanced  
46  
47 understanding of the multifaceted experiences of women who participated in CHIWOS.  
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49 The integration of cross-cutting themes like women-centred HIV care and the importance  
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51 of positive healthy actions in the summary diagram visually emphasizes the most crucial  
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3 issues for future research, thus contributing to the advancement of policy and  
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5 programming for women with HIV in Canada.  
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8           A main strength of this study is the richness of CHIWOS dataset analyses  
9  
10 conducted over the last 10 years. This study included publications from diverse authors  
11 and perspectives and focused on different topics and subsets of the CHIWOS participant  
12 population. This increased the reliability of the findings and ensured a full picture of the  
13 CHIWOS population's experiences was represented in the concept maps. Further  
14 strengthening this representation was the iterative and community-based nature of the  
15 concept mapping process itself. The process was driven by a diverse group of community  
16 members who amended the maps and diagrams through several rounds of consultations,  
17 which ensured their accuracy. While we recognize that the inclusion of publications  
18 under review or nearing publication may be perceived as a potential limitation due to the  
19 absence of peer review, we primarily interpret this as a strength. This decision allowed us  
20 to account for the inherent time lag between research analysis and formal publication,  
21 ensuring our analysis captures both established and emerging insights in the field.  
22 Furthermore, all "in progress" manuscripts included in this analysis have since been  
23 published, affirming the validity of our conclusions.  
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42           To prevent theme overrepresentation, we carefully examined the content of each  
43 conference abstract and publication to ensure duplicate results were not included. Some  
44 publications covered similar themes, such as disclosure, pregnancy loss, cervical cancer  
45 disparities, women-centred HIV care, help-seeking, the relationship between stigma and  
46 other factors, conception in serodiscordant couples, and issues specific to trans women.  
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54 However, there were nuanced differences with each of these themes. For instance, the  
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3 conference abstract focused on disclosure specifically addresses disclosure worries as a  
4 factor contributing to health outcomes, while the manuscripts explore experienced child  
5 abuse as a determinant of barriers to disclosure and awareness of the criminalization of  
6 disclosure. We find including these nuanced distinctions valuable, as concepts recurring  
7 in two or more composite concept maps were considered critical findings. Our rigorous  
8 approach to highlight crucial findings without data overrepresentation is a key strength of  
9 this study.  
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19 The co-creation of separate composite concept maps for cis and trans women  
20 shows the important similarities and differences between cis and trans women's  
21 experiences, and provides a unique perspective not explored in the individual concept  
22 maps. Our findings show many similarities in the health experiences of cis and trans  
23 women with HIV in CHIWOS were shared (21). This is important for providers who  
24 often assume providing care to trans women with HIV requires a unique skillset and  
25 approach (22). The key differences in the summary diagrams were gender affirmation at  
26 the individual level, as well as trans care knowledge and training at the structural level.  
27 Obtaining training in trans health and gender affirmation is a manageable goal that  
28 providers can achieve to deliver more competent care to trans women with HIV (23).  
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42 There are some limitations of this study . Efforts were made to engage lead  
43 investigators and community researchers from all provinces included in the CHIWOS  
44 study, but only academic researchers (not community researchers) from Quebec  
45 participated in this study. However, six manuscripts were included in production of the  
46 composite concept maps in which the first author was from Quebec and community  
47 members were involved in co-authoring these publications. In shaping our study, we  
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3 intentionally excluded manuscripts exclusively featuring qualitative data; a decision that  
4 might be seen as constraining the incorporation of certain insights. This choice was  
5 driven by the inherent challenges of equitably integrating qualitative and quantitative  
6 data, especially given the marked difference in sample sizes between the two types of  
7 manuscripts. To mitigate this limitation, we extensively involved community researchers  
8 in the concept mapping and summary diagram creation process, ensuring a  
9 comprehensive approach.  
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19 Recently, fellow CHIWOS investigators also employed mapping techniques to  
20 examine the experiences of women with HIV in accessing care. Skerritt et al. (24) used  
21 Fuzzy Cognitive Mapping, a participatory research method, to identify factors  
22 influencing satisfaction with HIV care and to understand engagement in the HIV care  
23 cascade. The Summary Fuzzy Cognitive Map they produced shows the weightings of  
24 categories influencing satisfaction of care, with the most significant being feeling safe  
25 and supported by healthcare providers, accessible services, and healthcare provider  
26 expertise (24). These mirror some of our findings in our composite concept maps 2 and 6  
27 which show the relationships among access to care, comprehensive care, and feelings of  
28 stigma. Both studies offer valuable visual insights into women's experiences,  
29 complementing each other and contributing to a comprehensive understanding when  
30 interpreted together.  
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47 Our study delved into the nuanced experiences of women with HIV through the  
48 lens of CHIWOS, examining psychosocial determinants, clinical aspects, mental health,  
49 sexual and reproductive health outcomes, and healthcare access and quality gaps to  
50 inform policy and programming for women with HIV in Canada. A recurring theme in  
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3 the composite concept maps and summary diagrams was the lack of receipt of  
4 comprehensive women-centred HIV care (3) including lack of discussion of reproductive  
5 goals, and access to care like gender affirmation. This finding suggests providers must  
6 improve knowledge through accessing clinical guidelines related to women with HIV  
7 such as the Canadian HIV Pregnancy Planning Guidelines, the Guidelines for the Use of  
8 Antiretroviral Agents in Adults and Adolescents with HIV, the British Columbia  
9 Guidelines for the Care of HIV Positive Pregnant Women & Interventions to Reduce  
10 Perinatal Transmission, and the Sherbourne's Guidelines for Gender-Affirming Primary  
11 Care (25-28). The composite concept maps also demonstrate the negative effects of low  
12 socioeconomic status and stigma and discrimination on women's self-reported resilience.  
13 This could impact the ability to self-advocate in healthcare settings, further affecting  
14 quality of care received. This finding has important implications to how clinicians and  
15 service providers approach care relationships and the importance of practicing from a  
16 person-centred lens.

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19 In exploring the intricate layers of women's experiences with HIV, composite  
20 concept maps 2, 3, and 4 show the profound impact stigma has on the lives of women  
21 with HIV. Societal stigma surrounding HIV not only amplifies the complexities of  
22 managing a chronic health condition, but also significantly contributes to heightened  
23 mental and emotional distress. Within this challenging context, resilience emerges as a  
24 pivotal force in composite concept maps 1 and 6. The intricate interplay between  
25 resilience and stigma reveals a dynamic process wherein women not only navigate  
26 adversity but also actively contribute to dismantling societal prejudices (29). These map  
27 contribute to a deeper understanding of the complex relationship between stigma,  
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3 resilience, and empowerment, which the Wheel of Resilience points to the need for a  
4 more supportive environment for women with HIV.  
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8 The interconnectedness between mental health and experiences of violence in  
9 adulthood further compounds the challenges women with HIV face, as depicted in  
10 composite concept maps 1-4. Women with HIV often contend with not only the  
11 physiological ramifications of the virus but also the psychological distress stemming from  
12 social stigma and potential encounters with violence. Composite concept map 3 highlights  
13 this especially for Indigenous women, who confront heightened violence in adulthood,  
14 likely due in part to the impact of historical and systemic factors such as colonialism and  
15 anti-Indigenous racism. While this trend was primarily noted among Indigenous women,  
16 it is probable that similar dynamics affect other racialized women as well. Composite  
17 concept map 2 introduces another dimension by revealing a correlation between  
18 experiencing violence in adulthood and a decrease in the utilization and adherence to  
19 cART. This clinical impact of violence emphasizes the pressing need for comprehensive  
20 trauma healing interventions. Evidently, the convergence of mental health, stigma, and  
21 violence presents significant obstacles for women with HIV to access adequate mental  
22 health support, worsening existing disparities. It is vital to address this complex  
23 relationship to develop a more holistic approach to care for women with HIV, ensuring  
24 much-needed interventions are not only medically effective but also tailored to women's  
25 unique health and holistic needs.  
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49 Another notable finding was the significance of positive healthy actions in the  
50 health experiences of women with HIV. This theme was evident in several composite  
51 concept maps, including map 1, which illustrated connections between social support and  
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3 reduced HIV-related stigma, and map 2, which demonstrated correlations between peer  
4 leadership involvement and increased awareness of ART prevention benefits. This finding  
5 has substantial policy implications, suggesting that investment in peer leadership and  
6 support programs for women with HIV can yield tangible mental and physical health  
7 benefits. Such proactive measures may contribute to a reduced burden on the greater  
8 healthcare system.  
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17 The next steps for policy advocacy are the co-development of a national women-  
18 centred HIV care (30) strategy that ensures equitable access to care including gender  
19 affirmation, and resource creation and education to increase knowledge about the health  
20 care gaps women with HIV experience in Canada. Since the completion of this study, the  
21 field of women-centred HIV care has experienced significant developments, including  
22 the publication of a Women-Centred HIV Care Model informed by CHIWOS findings in  
23 2021 (30), the launch of new women-specific HIV studies such as the British Columbia  
24 CARMA-CHIWOS (BCC3) study (31), and movement towards a National Action Plan to  
25 advance the sexual and reproductive health and rights of women with HIV in Canada  
26 (32). Aligned with these recent contributions, the findings from this concept mapping  
27 study underscore persisting unanswered questions and emphasize crucial future research  
28 priorities. One essential research focus that arises from our study is the need to develop  
29 and implement comprehensive women-centred HIV care strategies in clinical settings to  
30 facilitate translation of women's needs to their care providers, thereby influencing  
31 clinical measures of health and well-being. Moreover, our findings, coupled with insights  
32 from the broader literature (3,22,33-38) highlight the diversity among women with HIV,  
33 reflecting the varied nature of their needs. While the Women-Centred HIV Care Model  
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3 provides a solid foundation, it is evident that women's priorities and needs vary, often  
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5 shaped by other aspects of their identity including race and gender identity. Led by  
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7 members of the respective groups and individuals with lived experience, ongoing efforts  
8  
9 are being made to customize and tailor the Women-Centred HIV Care Model for priority  
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11 populations, including trans women, African, Caribbean, and Black women, as well as  
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13 Indigenous women. Our findings also highlight the need to investigate the intersection of  
14  
15 mental health, stigma, trauma and violence and its impact on the wellbeing of women  
16  
17 with HIV, as well as to develop trauma-informed strategies, approaches and  
18  
19 programming aimed at addressing these intersecting factors. In summary, future research  
20  
21 should concentrate on developing positive and health-oriented actions and programs  
22  
23 tailored to women with HIV, incorporating an intersectional perspective. These efforts  
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25 should not only address the unique needs shaped by diverse aspects of identity, but also  
26  
27 offer leadership and capacity-building opportunities for peer-led initiatives centered  
28  
29 around self-care and wellbeing.  
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## 35 CONCLUSION

36  
37 We developed a unifying summary of the health experience of women with HIV in  
38  
39 Canada by applying concept mapping to 60 CHIWOS publications. The produced visuals  
40  
41 can be used to inform policy and programming by providing easy to understand evidence  
42  
43 on gaps related to the social determinants of health including housing, food security, and  
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45 income, in addition to structural barriers such as multiple areas of discrimination.  
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47 Importantly, these visuals promote strength-based approaches to women with HIV's  
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49 health and wellbeing. The results of this study should guide future research and care  
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51 priorities for women with HIV in Canada, placing a specific emphasis on trauma-  
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3 informed, peer-led positive healthy actions accessible to women in all their diversity.  
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5 This includes initiatives aimed at enhancing women-centred HIV care and self-care to  
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7 comprehensively improve the holistic wellbeing of women with HIV.  
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24  
25  
26  
27

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29  
30 AY, PM, MK, and BG contributed to the preparation, participant recruitment, and  
31 publication screening process. AY, PM, MK, and ML participated in the development of  
32 concept maps and summary diagrams. PM, JK, and ML wrote the first draft of the  
33 manuscript. VN, RG, PF, YP, NO, BG, BB, SS, MN, AF, BG, CC, KW, MS, AL, CL,  
34 AP, AK, and ML provided feedback and edits on all the visuals and versions of the  
35 manuscripts. All authors have read and agreed to the published version of the manuscript.  
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53 **Competing interests:** None declared.  
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3 **Patient and public involvement:** Patients and/or the public were involved in the design,  
4  
5 conduct, or dissemination plans of this research. Refer to the Methods for further details.  
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8 **Data availability statement:** No additional data available.  
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10 **Ethics approval and consent to participate:** The study was assessed by the research  
11  
12 ethics board at Women's College Hospital to not require ethical approval by a human  
13  
14 research ethics committee because the Ethical Principles for Medical Research Involving  
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16 Human Subjects did not apply. We obtained informed consent from all participants in  
17  
18 CHIWOS. Refer to the Methods for further details.  
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3 **FIGURE TITLES**  
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5 **Figure 1.** Applying the Eligibility Criteria to CHIWOS Publications  
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7 **Figure 2.** Example of an individual concept map from one publication (Access to Care,  
8 Kronfil et al., 2017)  
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10 **Figure 3.** CHIWOS Summary Diagram – Honouring the Experiences of Women with  
11 HIV  
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13 **Figure 4.** CHIWOS Summary Diagram – Honouring the Experiences of Trans Women  
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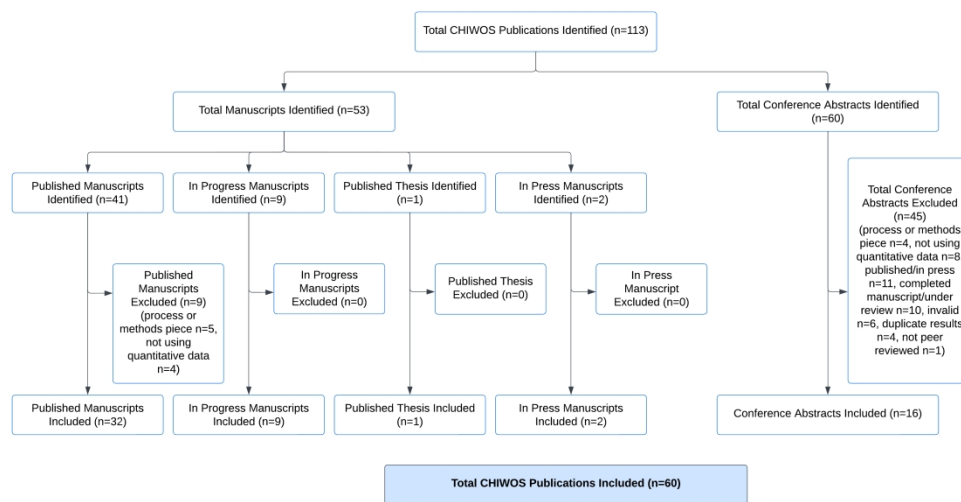


Figure 1: Applying the Eligibility Criteria to CHIWOS Publications

801x427mm (118 x 118 DPI)

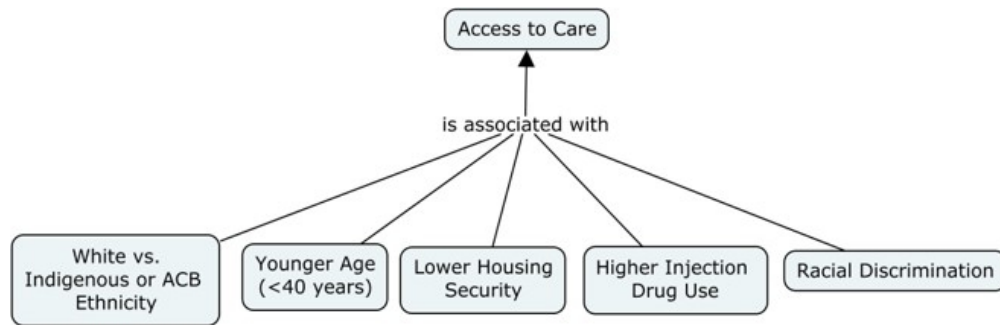


Figure 2: Example of an individual concept map from one publication (Access to Care, Kronfil et al., 2017)

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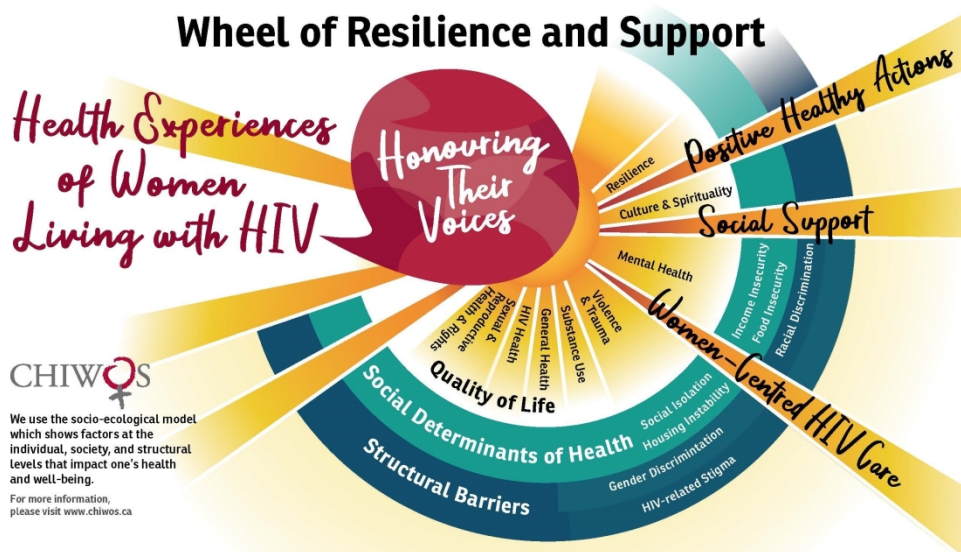


Figure 3: CHIWOS Summary Diagram – Honouring the Experiences of Women with HIV

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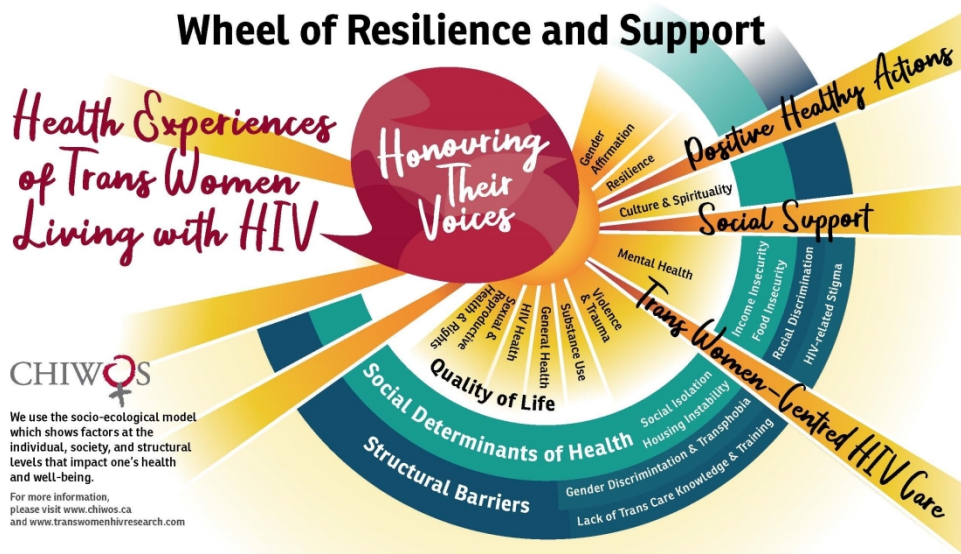


Figure 4: CHIWOS Summary Diagram – Honouring the Experiences of Trans Women Living with HIV

338x190mm (200 x 200 DPI)

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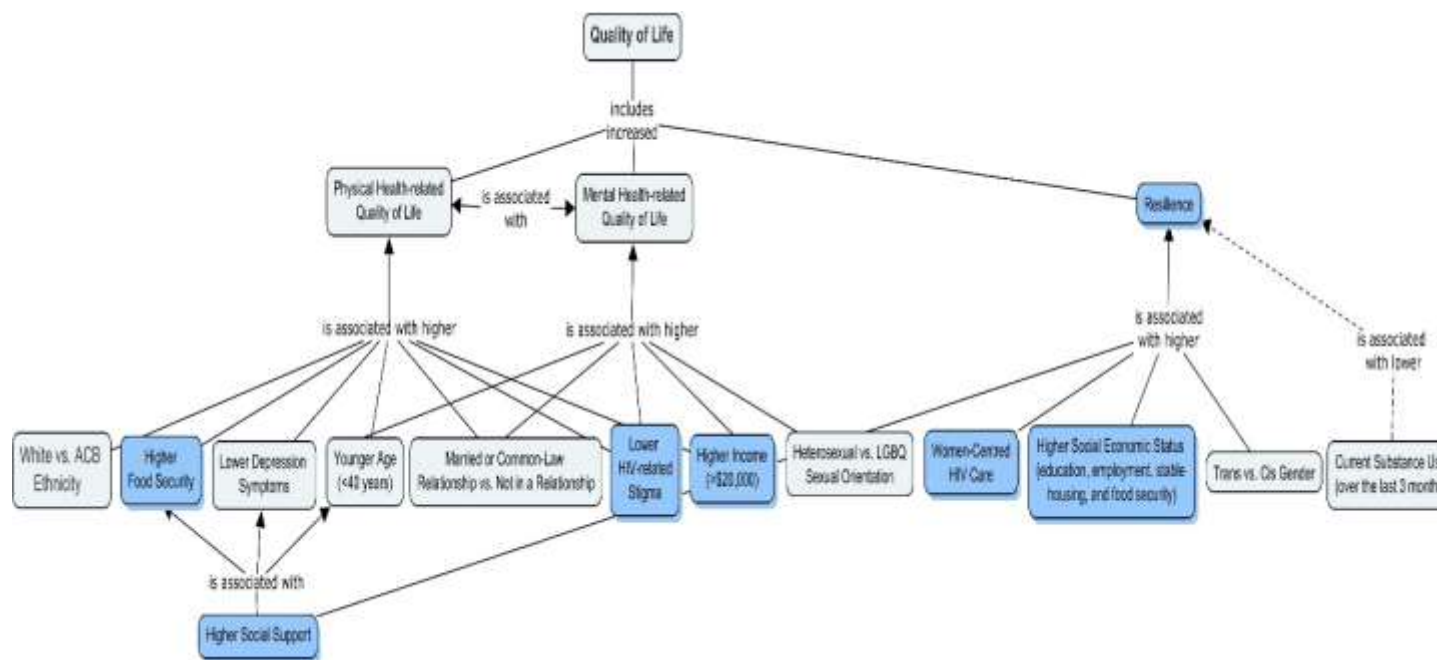
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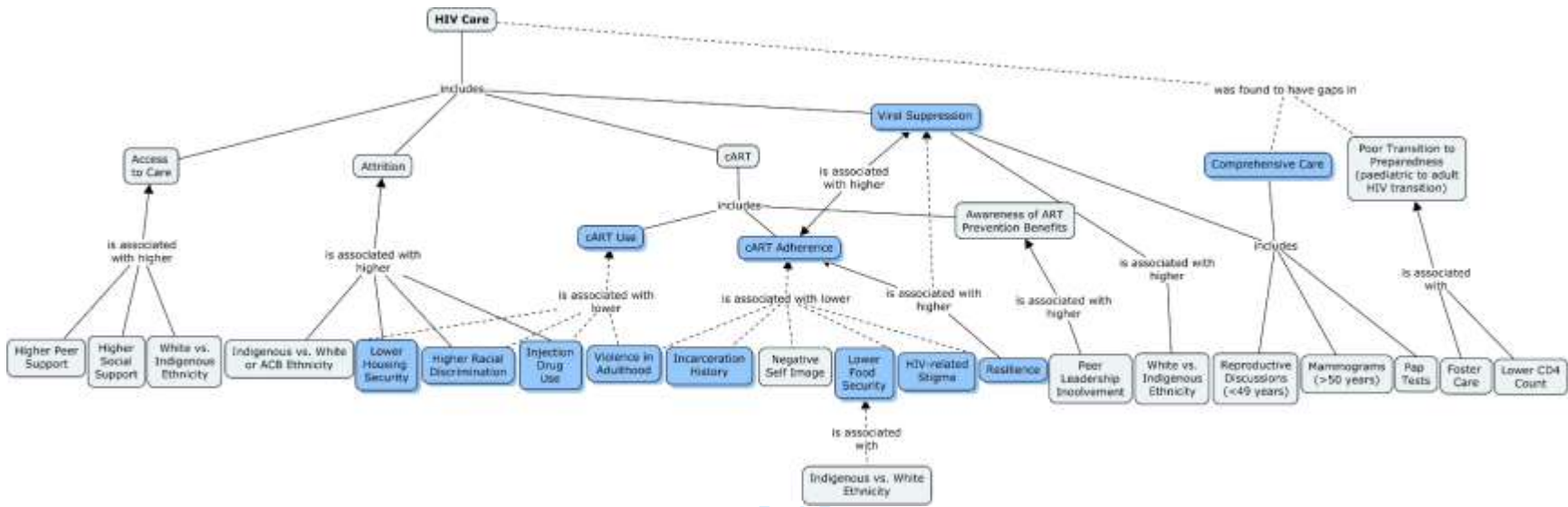


Supplementary Figure 1: Quality of Life Concept Map



Our definition of Quality of Life (QOL) extends beyond one’s physical and mental health status. It is expanded to also include QOL’s relationship with resilience and overall wellbeing. QOL was measured using the SF-12 scale.

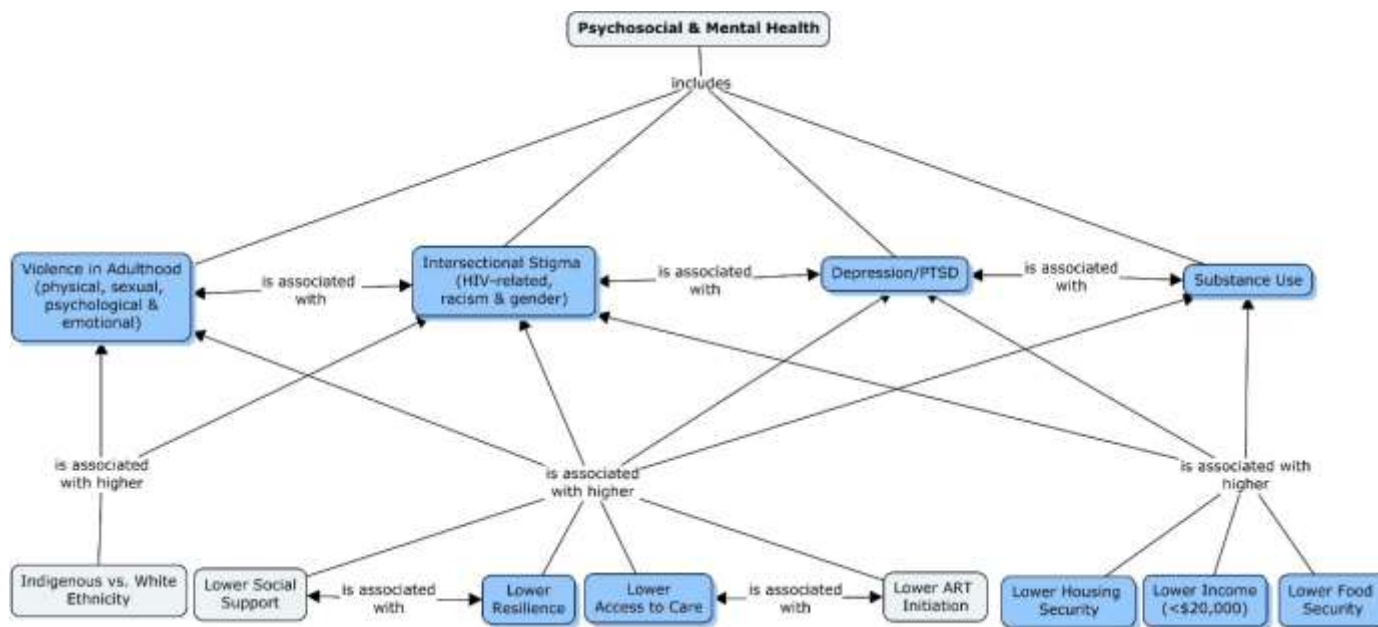
Supplementary Figure 2: HIV Care Concept Map



Attrition refers to reduction in the % at each stage of the HIV care cascade. These stages are: 1) access to care, 2) cART use, 3) cART adherence, and 4) viral suppression.

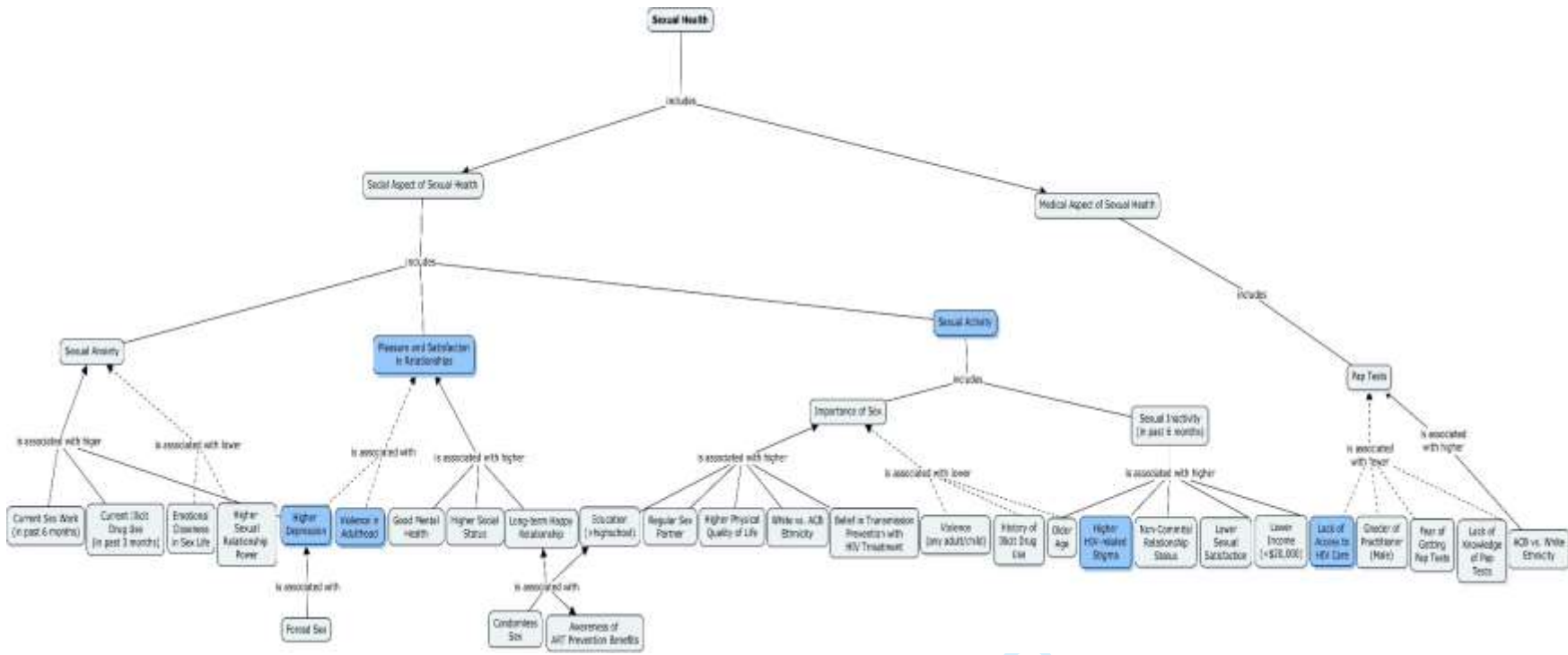
Comprehensive care is defined by four indicators: Pap test, viral load suppression, reproductive discussions, and mammograms.

Supplementary Figure 3: Psychosocial and Mental Health Concept Map



Intersectional stigma, violence, depression/PTSD, and substance use are associated with each other. Also, access to care was measured using the Barriers to Access to Care 12-item scale.

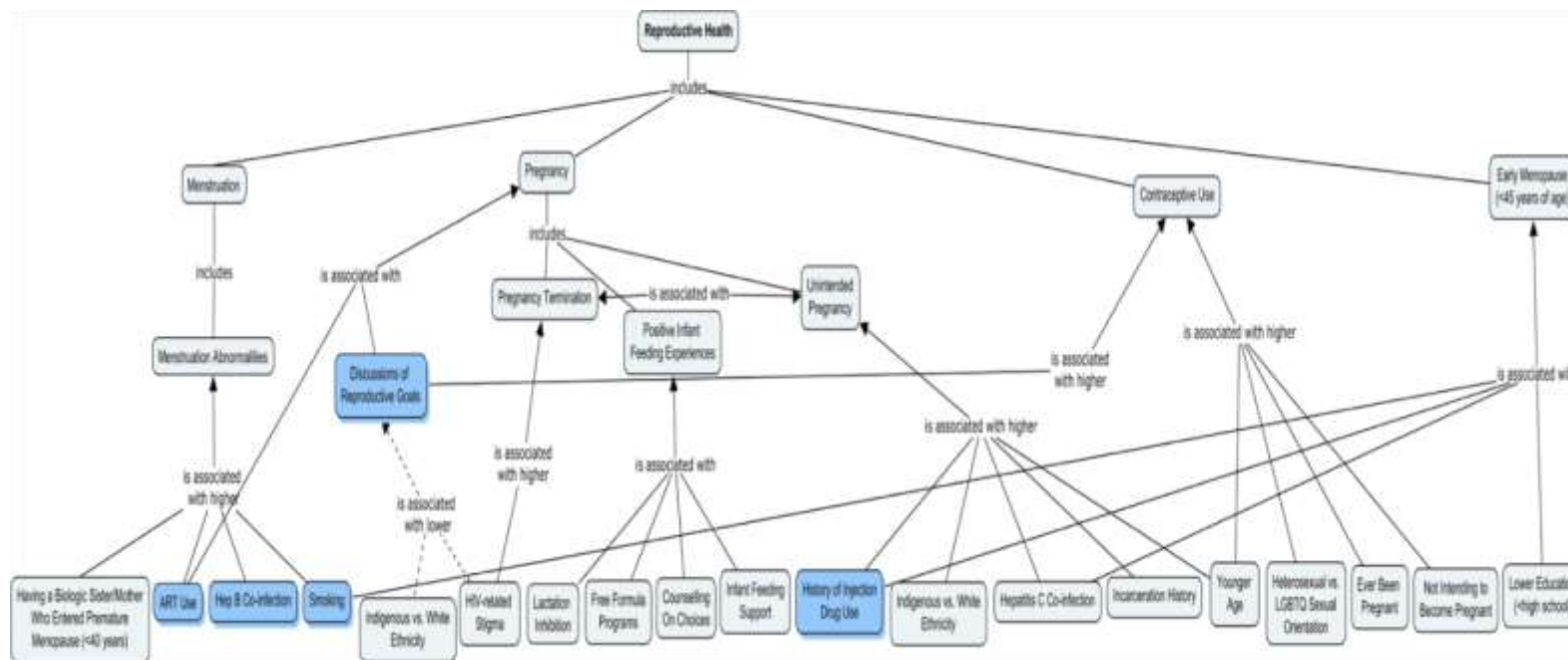
Supplementary Figure 4: Sexual Health Concept Map



There are various medical aspects of sexual health, including the experiences and management of sexually transmitted infections; however, CHIWOS has not yet analyzed data on them.

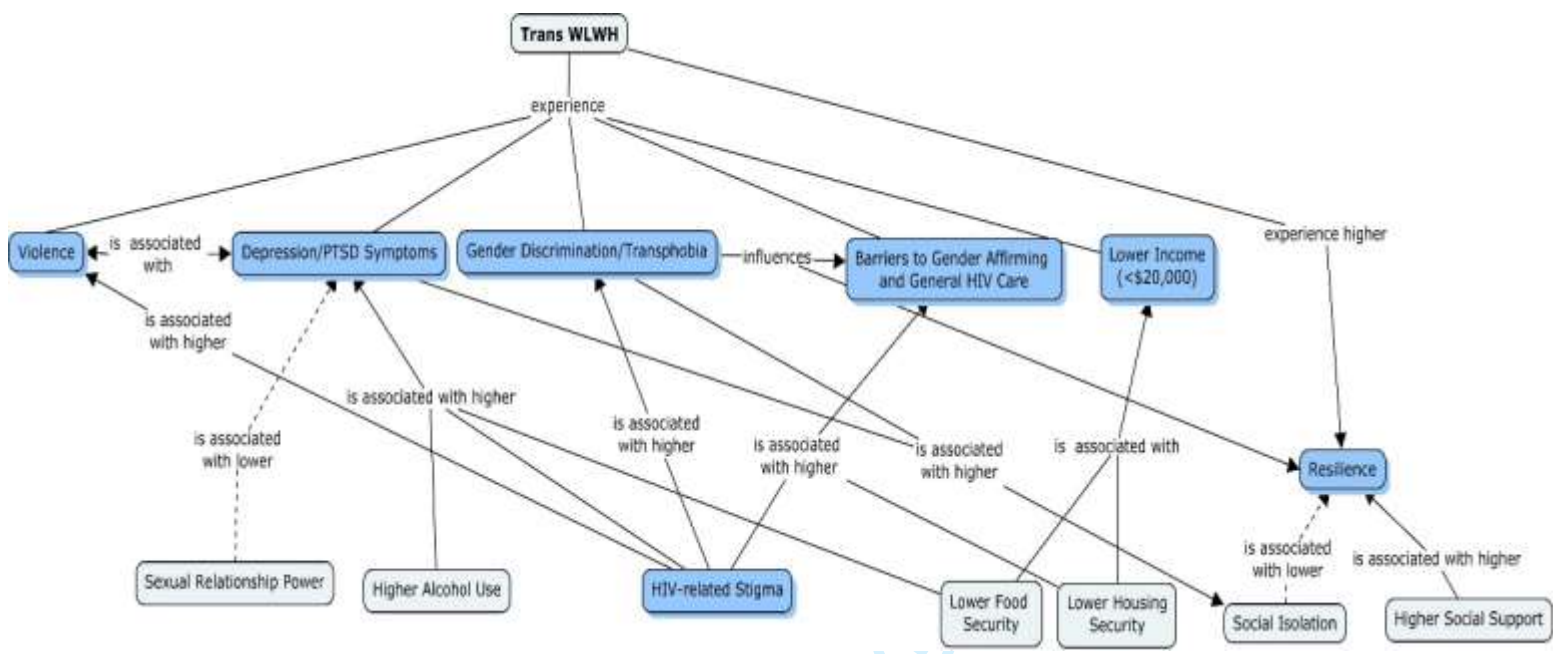
Sexual activity was defined as consensual sex (oral or penetrative) in the past six months based on the questionnaire used; but it is understood to represent much more including sexual desire, sexual needs, sexual being, and more.

Supplementary Figure 5: Reproductive Health Concept Map



CHIWOS findings showed a narrow range of contraceptive methods used.

Supplementary Figure 6: Trans WLWHIV Concept Map



Social isolation is the absence of social and economic supports (i.e., lower income, housing, and food services) which are barriers to ongoing engagement in HIV care. These variables are in comparison to cis-gender women.