MY BODY, MY STORY

Body Mapping and HIV Treatment Side Effects Project Report

ICW

INTERNATIONAL COMMUNITY OF
WOMEN LIVING WITH HIV

The content of this report is based on two body mapping workshops conducted in Ottawa and Toronto, Canada. These workshops and the material developed subsequently were funded by the Women's College Hospital (Women's Xchange program). The report was prepared by Marilou Gagnon, RN, PhD (Associate Professor in Nursing at the University of Ottawa), Carmen Logie, MSW, PhD¸ (Assistant Professor in Social Work at the University of Toronto), and Jessica Whitbread, MES (ICW Community Relations and Mobilization Manager) with the precious feedback of women who attended the workshops.

The **International Community of Women Living with HIV/AIDS** (ICW) exists to lead efforts towards securing and improving the quality of life for women living with HIV. We do this by mobilizing, organizing, advocating, mentoring and raising consciousness on the issues that directly impact our lives. ICW is the only global network by and for women living with HIV. The network was established in 1992 as a response to the consistent silencing and marginalization of women's voices within the HIV response. ICW works in 120 countries through regional networks each led by and for women living with HIV around the world, including Asia Pacific, Caribbean, Central Africa, East Africa, Europe and Central Asia, Latin America, the Middle East and North Africa, North America Southern Africa, and West Africa—and the chapter for young women, adolescents and girls. Bringing together women living with HIV worldwide around the common call "Nothing for us, without us", ICW plays a vital role in ensuring that women living with HIV, regardless of age and in all their diversity are leaders in HIV advocacy and policy and in securing human rights for women living with HIV. ICW has been at the forefront of securing the sexual and reproductive health and rights of women living with HIV at the local, regional and global levels since its inception.

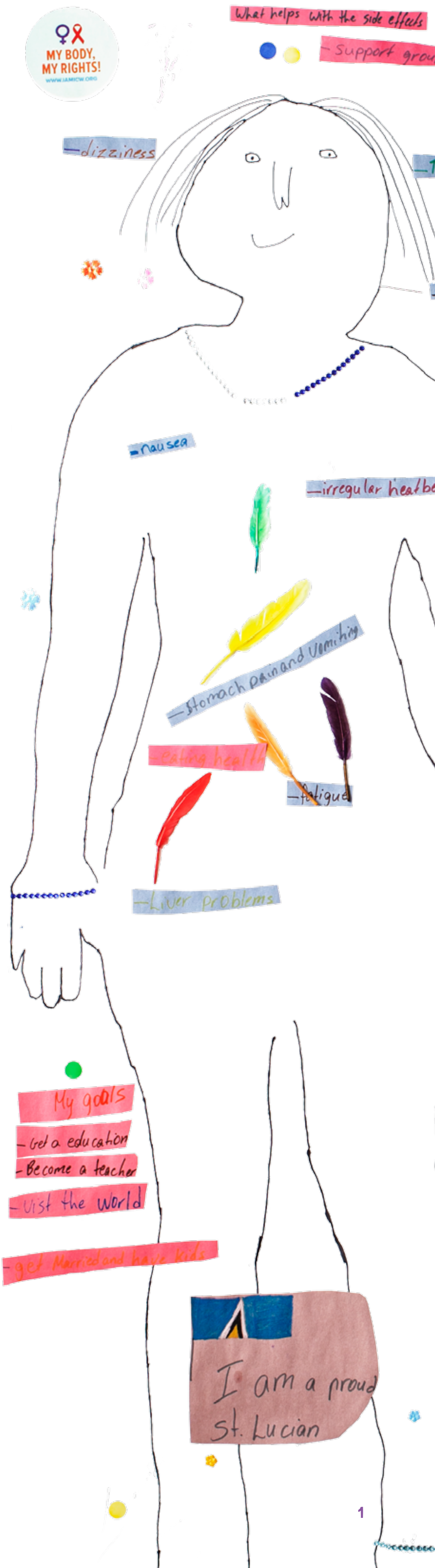
April 2017

WOMEN AND SIDE EFFECTS

Each of the antiretroviral drugs that are used in combination to treat HIV infection causes a range of side effects. These side effects continue to have a significant impact on the lives of people living with HIV in spite of the use of newer drugs and claims that antiretroviral combination therapy is now more “manageable” and less toxic. This is particularly true for women living with HIV. Women are not only more likely to experience side effects than men, but they also experience different and often more severe side effects when compared to men on the same drug regimens. Yet, women continue to be underrepresented in trials and research. In other words, women continue to take antiretroviral drugs that have been tested and studied largely on men.

Research suggests that women living with HIV also experience side effects differently than men because their bodies react differently to the drugs. They also experience side effects differently because of their exposure to gendered expectations surrounding their bodies, sexuality, and femininity, their interactions with physicians and other health care providers which can be challenging at times, and their individual situations with respect to side effects (i.e., not knowing enough about them, not being heard, not knowing what to do, not being able to “manage” them). Research also suggests that women are more likely to have low treatment adherence and poor clinical outcomes largely because of side effects. Despite this, we know very little about the experiences of women living with HIV.

Side effects can have social, psychological, emotional, and physical impacts. They can change or limit relationships with family, friends, and partners; they can create additional stress and feelings of sadness, isolation, anger, despair, and shame; they can make women feel sick and cause new health issues; they can make it harder to take antiretroviral drugs and maintain an undetectable viral load; and finally, they can decrease quality of life and the overall well-being. This is why we need to talk about them and try to find better ways to support women. The goal of this project was to document women’s experiences of side effects using **body mapping**, an arts-based approach that is used to create a life-size map of your body and experience. We wanted to learn from the personal stories of women and start developing new ways of understanding, talking about, and dealing with side effects. This report is only the beginning …



BODY MAPPING

Body mapping is an arts-based participatory method that can be used for self-reflection, therapy, and/or research. It helps to better understand the experience of taking medications and living with side effects. Body mapping takes the real-life size drawing of the body as its starting point and allows you to tell your own story using art supplies and other relevant materials (magazines, pictures, symbolic objects). The final product is a picture of your personal story.

HOW TO CREATE YOUR BODY MAP

Think of the body position that best represents you. Lay down on a large piece of paper and ask someone to trace the outline of your body.

Start at the feet. The feet represent your roots, where you come from: a home, a country, a family, a culture, and so on. It represents your beginning.

Go to the head. The head represents the dreams, goals, and aspirations. What you want to achieve, who you want to be, where you want to go. The head represents your future.

Draw a path between your feet and your head; between your past and your future. This is your journey; a personal journey that is unique to you. What happened along the way?

Finally, use the inside of the body to show what it means to take antiretroviral drugs and live with side effects. What are your side effects? How do they affect or change your body? How do they make you feel? Where are they located in your body?

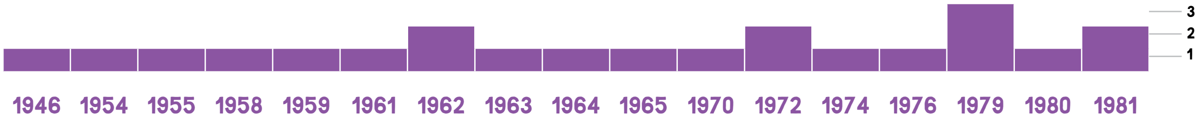
Reflect on your map. Share it with others if you want.

TELL YOUR STORY.

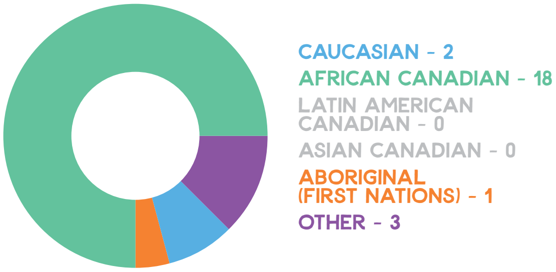
THIS IS MY STORY

We asked women to share their story using body mapping. A total of 26 women took part in the two workshops: 9 in Ottawa and 17 in Toronto. Here is a brief summary of the information they provided on age, ethnicity, education, income, year of diagnosis, and year of first treatment. (N=24)

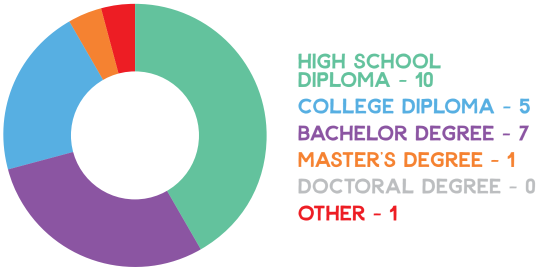
AGE (YEAR OF BIRTH)



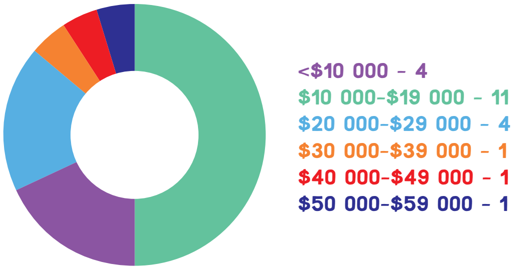
ETHNICITY (N=24)



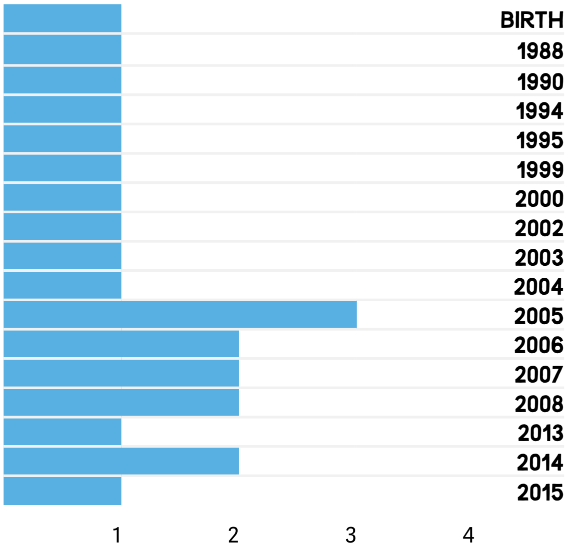
EDUCATION



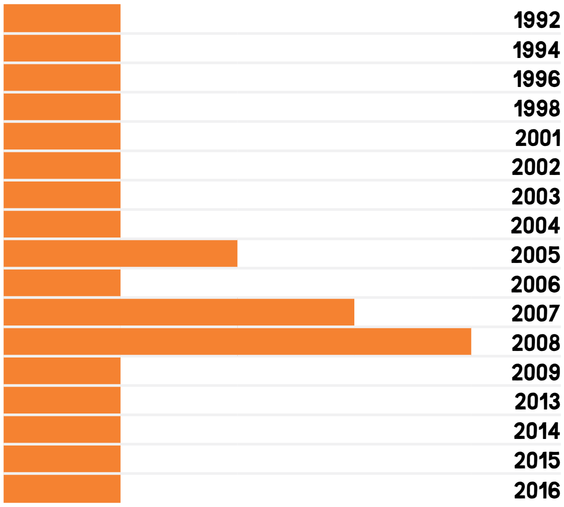
INCOME (N=22)



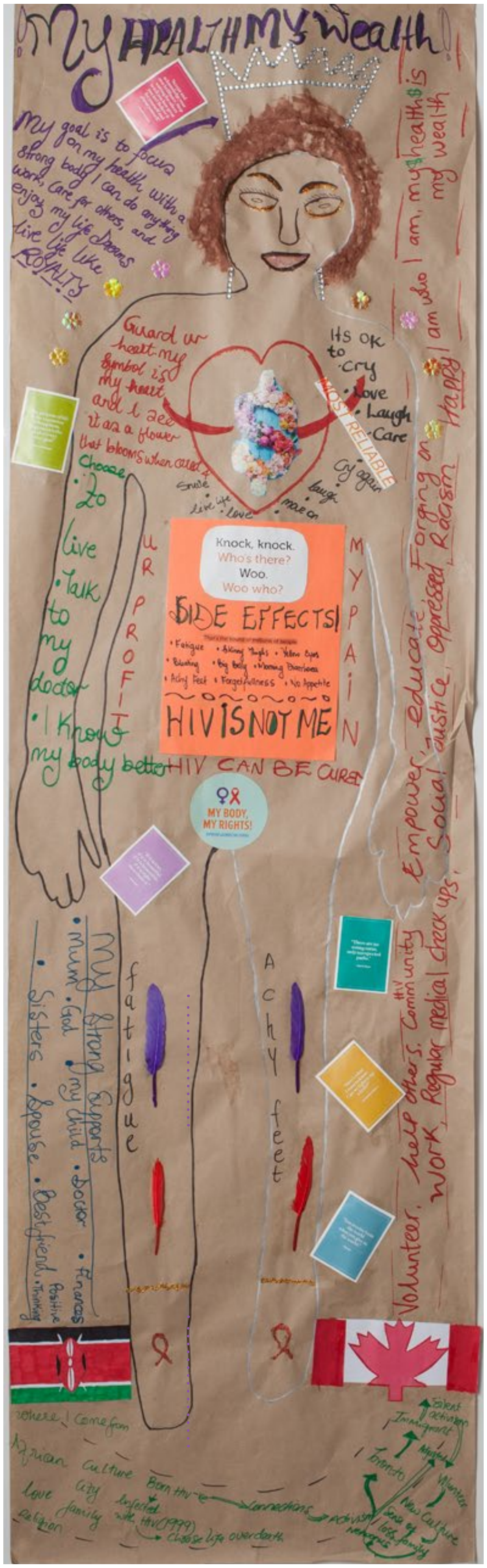
YEAR OF DIAGNOSIS



YEAR OF FIRST TREATMENT



EACH MAP TELLS A UNIQUE STORY.
WE LOOKED FOR COMMON THEMES AND THIS IS WHAT WE FOUND.



My story begins at the time of my diagnosis.

My story begins in my home country. I had to leave my home country because of conflict, war, work, family.

My story begins with me being very sick from HIV. I was hospitalized and I was wondering what would happen next.

At the beginning, it was hard.

I experienced stigma, discrimination, fear, isolation, lack of support, loss of hope, and difficulty accepting my diagnosis.

Some things helped. Love and support from family, friends, health care providers, community workers, counselors were very helpful. Spirituality also made a difference for me. These things still help today.

Over the years, I followed a path. I kept climbing up. Not letting anything take me down.

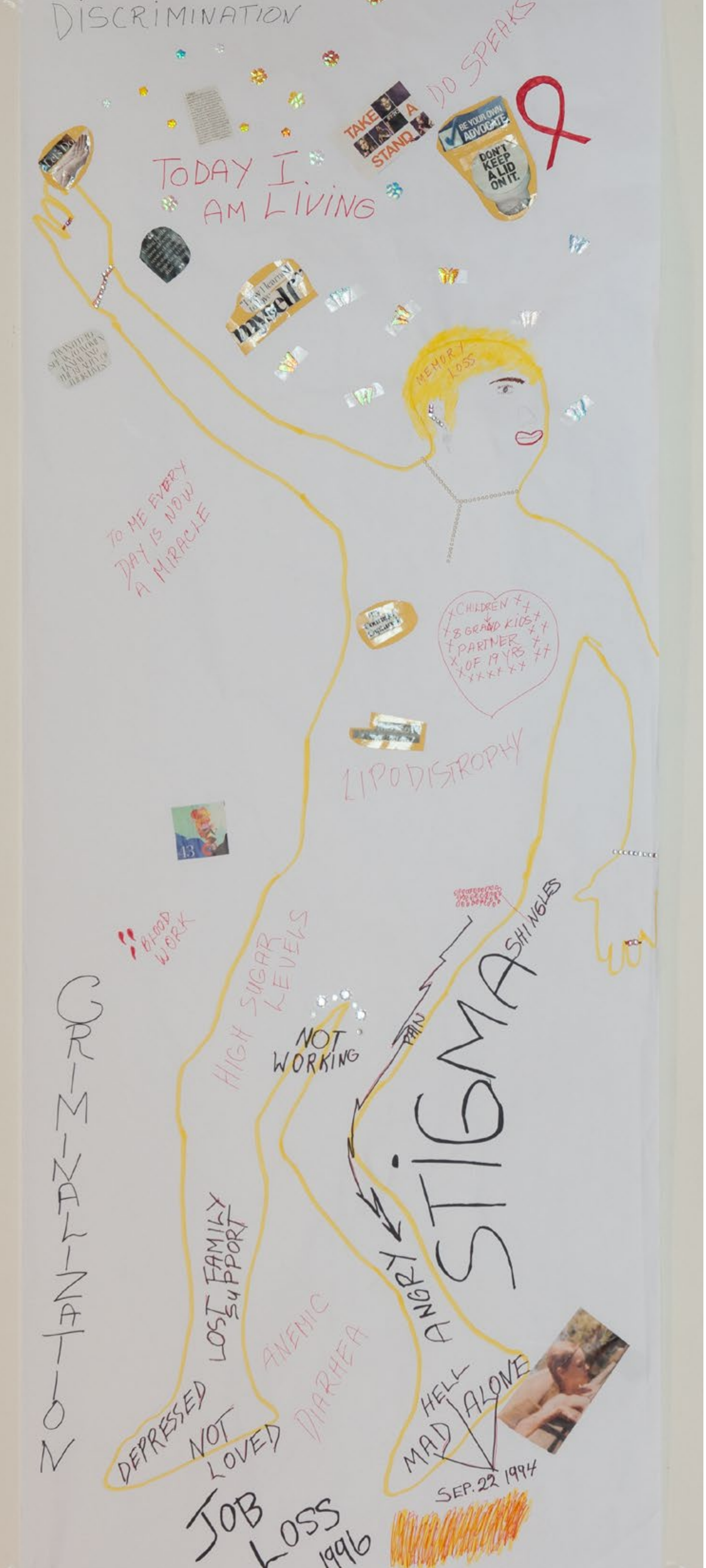
Along the path, I became sick, I was hospitalized, and I became healthy again. I raised my kids and continued to provide for my family. I took medications, changed my medications, and sometimes, I stopped or did not take my medications. It was not always easy. I developed different side effects and that had an impact on my life. I learned to manage my health and my HIV. In the process, I learned about myself. I dealt with disclosure, stress and stigma. I worked hard to deal with trauma I experienced and became sober – I'm really proud about that. I worked hard, I volunteered. I made new friends. I lost loved ones. I went back to school and even learned a new language. Eventually, I finally got my citizenship.

Challenges remain, but it's so much different now. I am a survivor. I am alive. I know my body better. I love myself. I am positive. I am thankful. I have hope. I have dreams. I don't apologize for who I am and what I am. I tell it like it is.

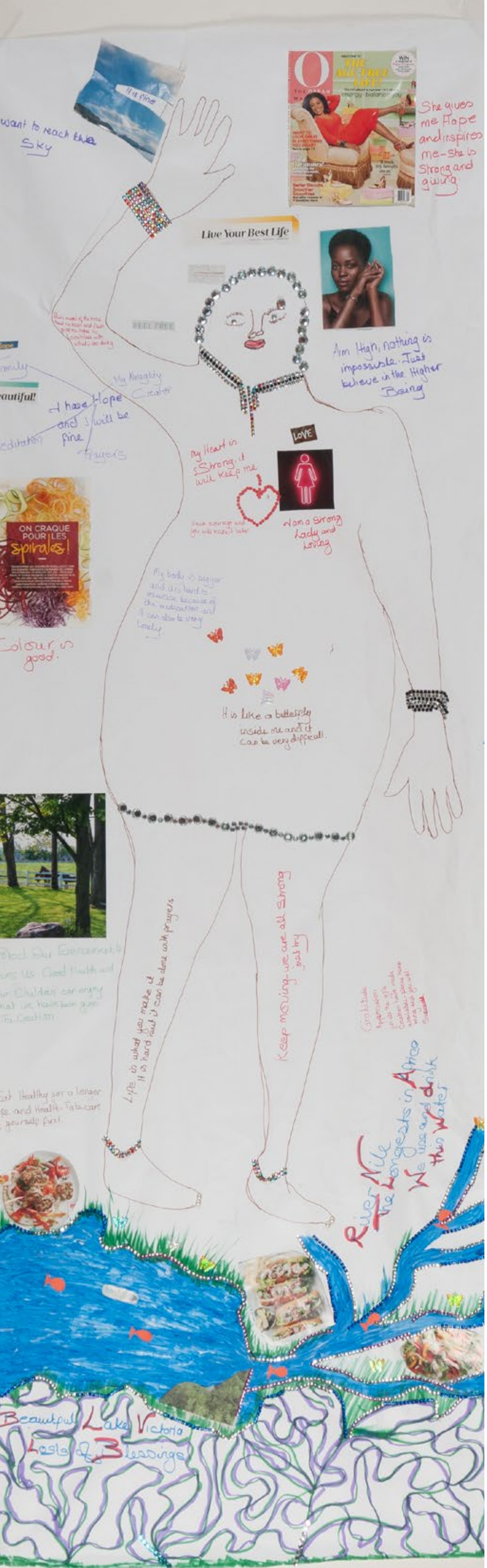
My health is my wealth

SIDE EFFECTS

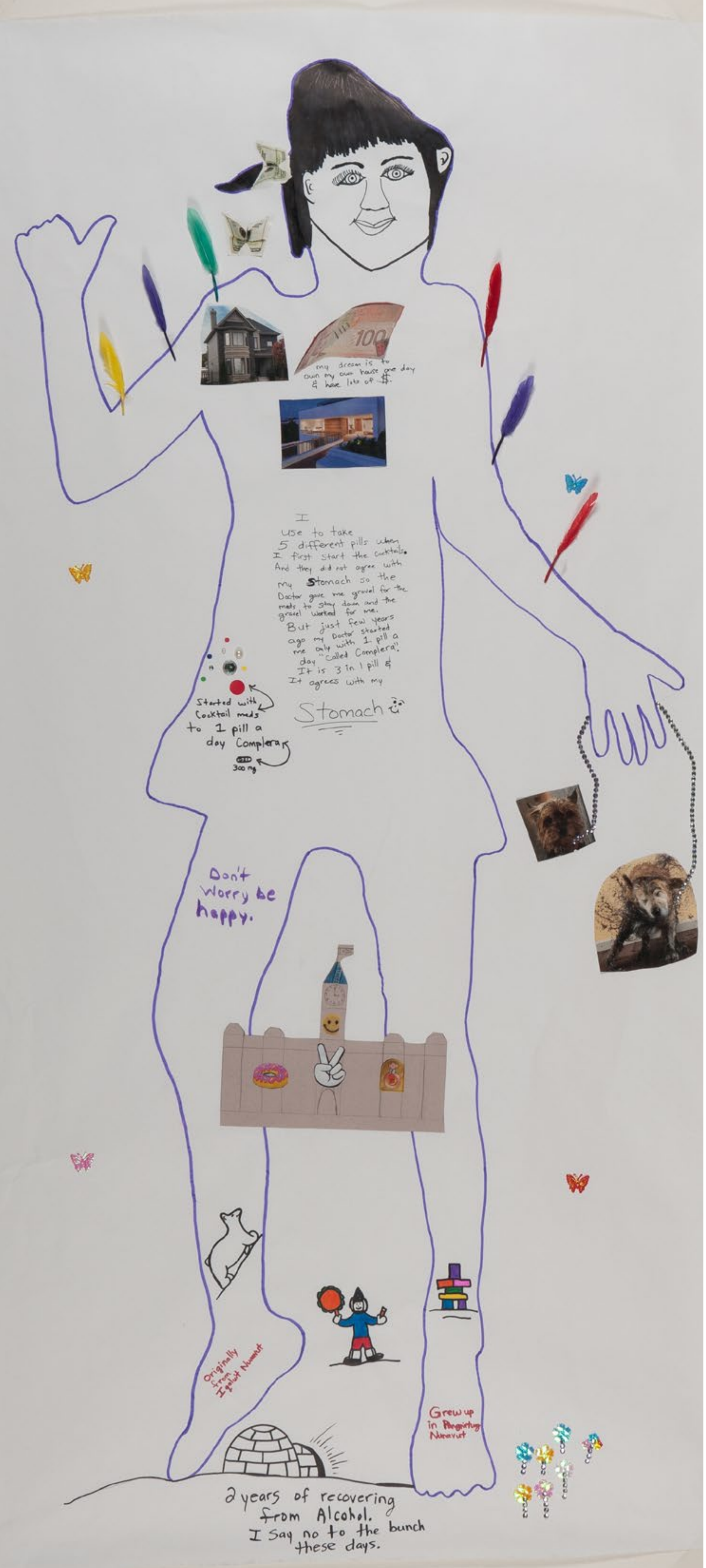
Side effects are part of the journey. But they are not a stand-alone issue. They are influenced by context and environment, life situation and priorities, income and access to resources to deal with side effects (i.e., nutritional supplements, medications, prescribed cannabis), access to information and support, quality of care provided by the health care and services provided by community-based organizations, access to specialists including physiotherapists and nutritionists, and so forth. It is important to take everything into consideration. This is what some of the women had to say about their experience with side effects.



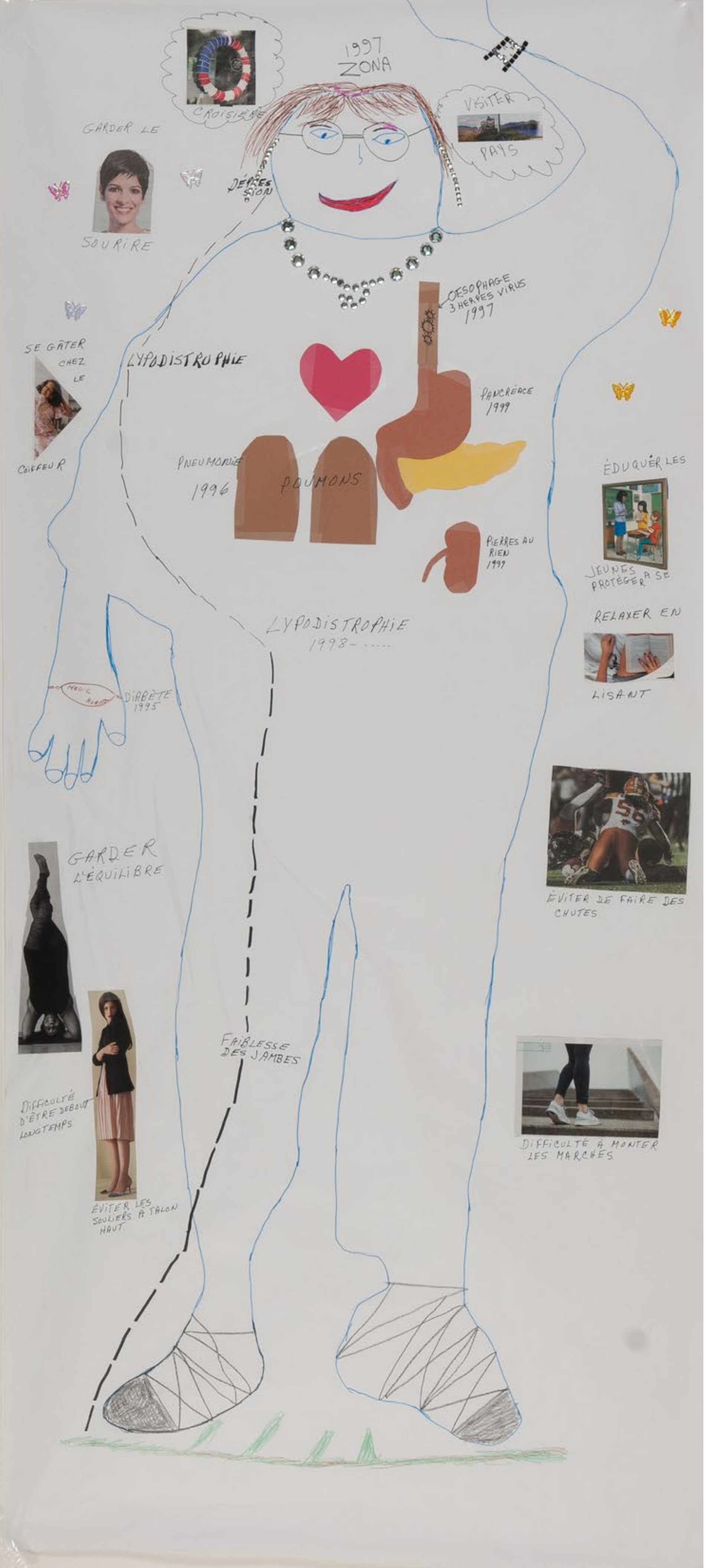
"I suffer from memory loss and that's very disturbing for me. I'm in a middle of a sentence and I can't remember what I'm looking for and I feel embarrassed because I can't remember the simplest words. I can't remember sometimes what I did the day before or as I can remember a month before or a couple years ago, I can remember things but I can't remember sometimes what I did the day before you know, that is disturbing, very, very disturbing."



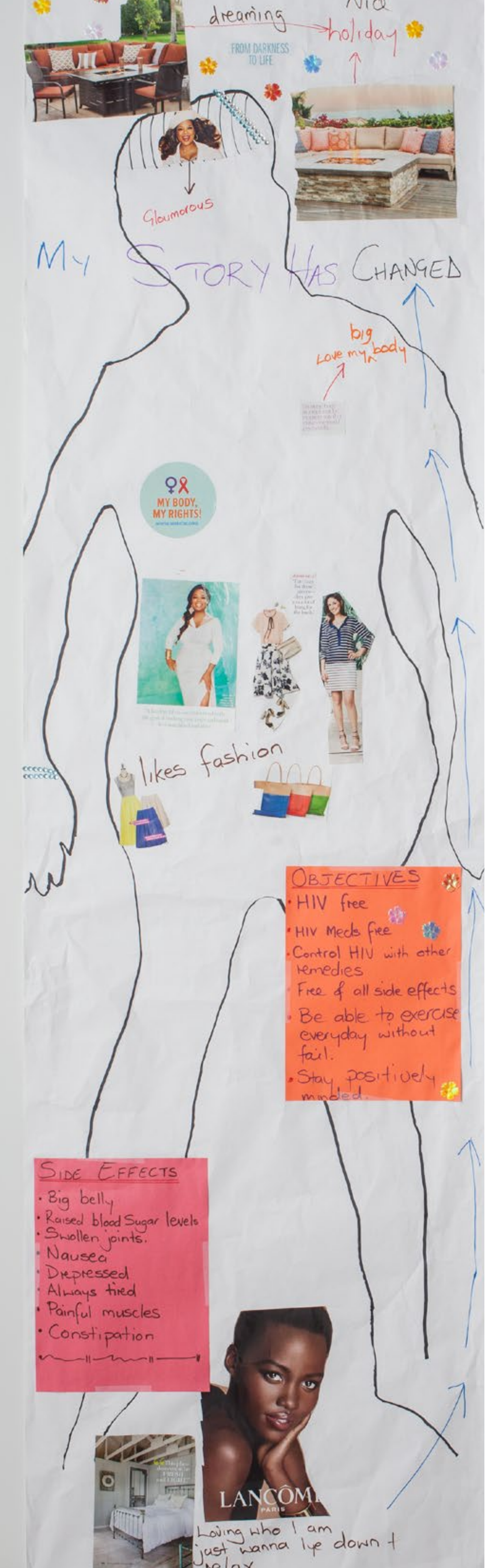
“Personally I have hope and hope as kept me going, so after 2 years in Canada, I started my medication, I was on three medication by that time, then at one point I had like swelling on my body, so I had to go to my doctor and they had to change the medication but at the same time I had to leave my doctor, my previous doctor and move to another doctor because I told him that I’m having swelling and I don’t know what is happening until my family doctor say that this is the side effect of the medication and she wrote a note to my doctor to discontinue the medication”



"When I first started the medications, they weren't agreeing with my stomach so the doctor gave me Gravol to put, let them to stay down and so I didn't want to take the medications after a while because I got tired of puking and, but with the Gravol it was helping back then and there was a few times that I stopped it because I didn't like taking a bunch of pills every day I guess, but few years ago, I got to take one pill a day now and I'm happy with that. I don't puke and so I'm happy with that one pill a day"

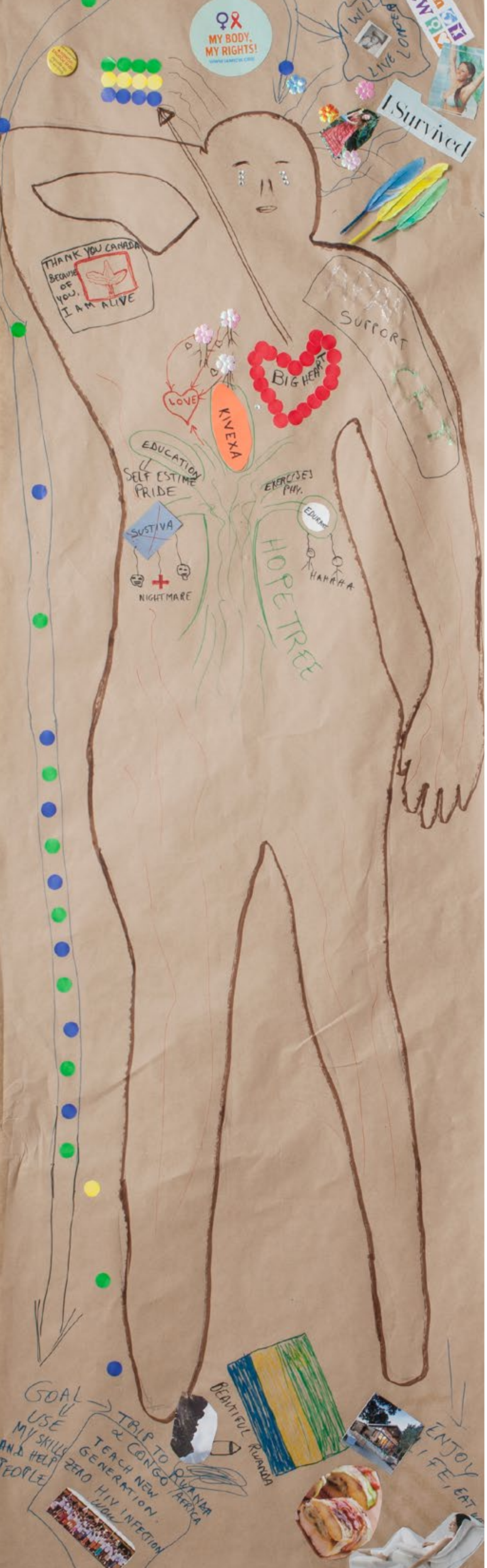


"In 1998, I ended up with lipodystrophy, that's fat accumulation in my belly and my arms. That doesn't prevent me from doing anything, but it is heavy to carry. I have problems with my legs. I have a hard time going up the stairs. I have to hold the ramp to go up the stairs and I have trouble standing up for a long time. I can't wear high heels anymore. That's a big no for me so I have to wear flat shoes. I try to keep my balance when standing up because of my legs. I also ended up with diabetes in 1995 because of the medication ddI, it's called Videx now."

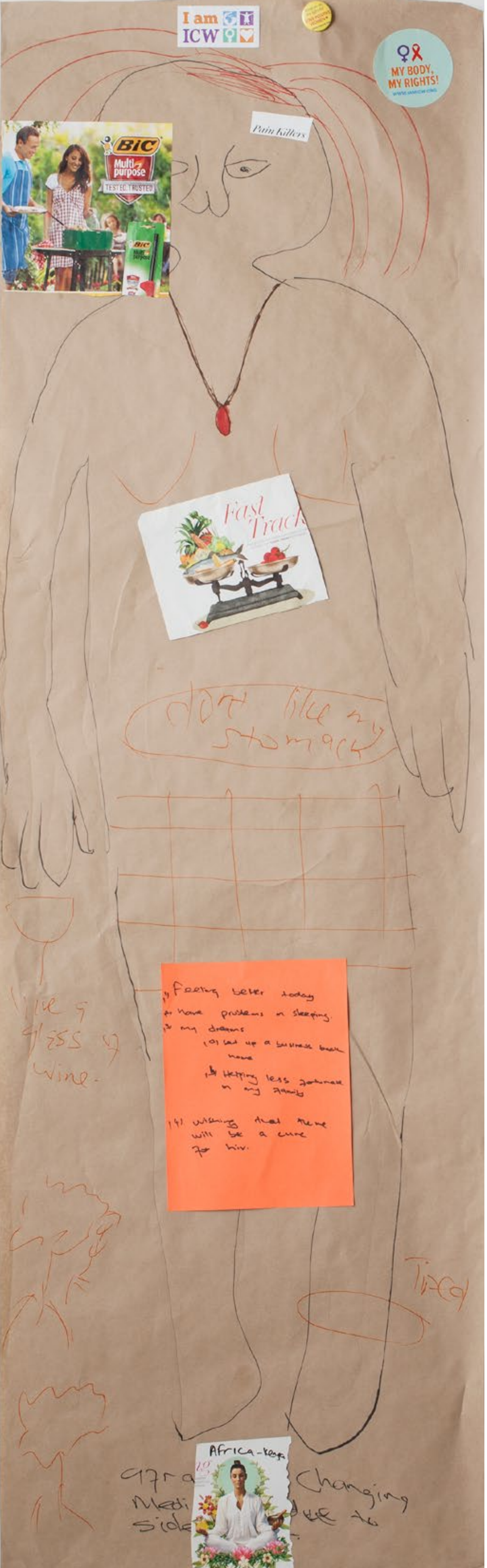


"I just love my big body, you know, it's one of the side effects, I keep putting on weight since I've changed my medication but to the doctors, you know, they just say: "maybe you have changed the way you are eating and what have you, you need to diet, you need to exercise" but to me, I just feel no, something is not normal because I haven't tried to change my diet. But I'm still getting big and my sugar levels, they keep very high. They can't find a way to put them down, that's another, another big issue for me and most of the times I'm depressed. Just like I'm sitting, I haven't talked to anyone, so I just feel depressed and I have painful muscles and constipation has become a big issue with me although I'm still dreaming big. And so, I've reach in there my story has changed because since when I was diagnosed, you know up to now, I'm living with it, I'm loving it, you know, whatever comes, big body, you know hacking muscles, I'm just living with it. I'm loving my body."

“I worry about the future, you see the brain up there with the little red dot, that’s like reservoirs of HIV hiding in places where HIV hides and who knows what it’s doing to me. I hope that it’s not doing much, I do the testing to see if it’s doing, affecting my cognition, my memory, blah, blah, blah. And you know, I try to keep on top of that but anyway, if it does affect me then, what are the consequences for me? I don’t know. It’s just like you know, the gut stuff. It’s taking a lot of energy, you know like, it’s a lot of hard work being HIV positive, you have to look at your health constantly and be vigilant and go to the naturopractic doctor on a regular basis and follow all the directions and when I was dealing with this gut turmoil, I was given like five or six different kind of things to do to help me which, you know I really appreciate but ok, some of them I take with food, some of them I don’t take with food, they have to be like four hours apart, some of them have to be two hours apart, two before and six after and it’s like Oh my god, it’s like a whole time table here, juggling all of this stuff is really hard work, it’s hard work being HIV positive.”

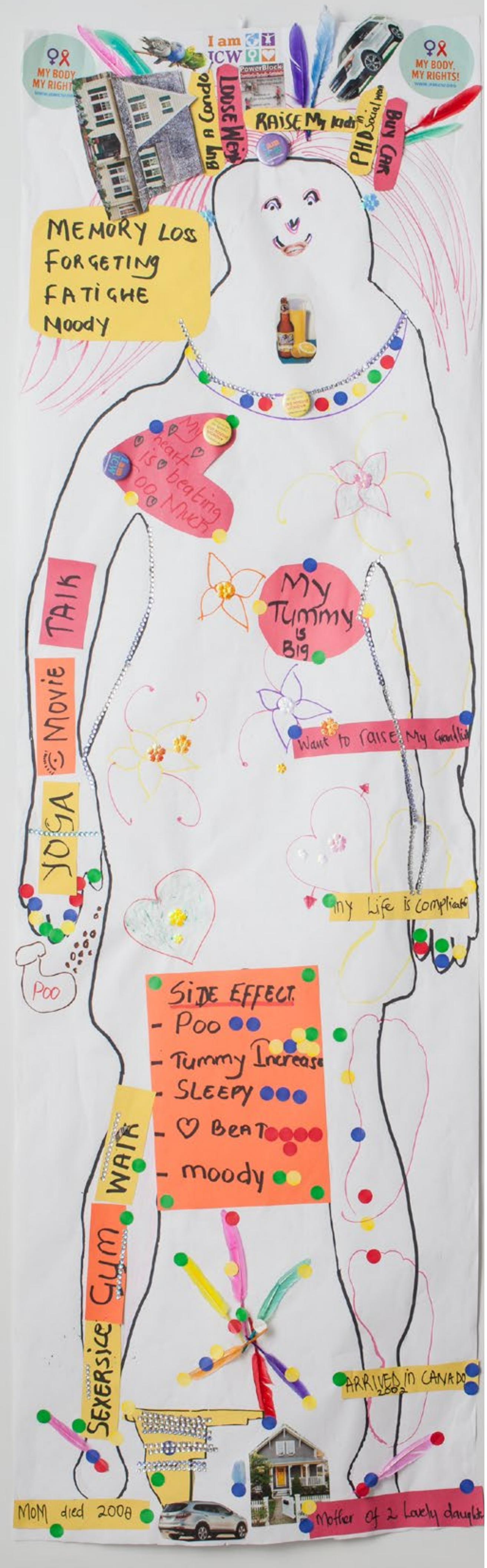


"I took the Sustiva and Kivexa. So this Sustiva was a nightmare for me. For five years I took this medication and I have nightmare every single night. I went to the doctor and the doctor told me that I have to change the medication and so I changed the medication to a new one Edurant and I started feeling good. About the side effects, I remember my shape before, before starting the treatment. I was a very nice woman, really beautiful. A nice shape, now, now I start seeing big boobs, big belly. My legs were transformed, they changed completely and I said "Oh my god", I started hating myself. I loved dresses but I couldn't put on dresses anymore. I remember one day I went back home and everybody was shouting on me. What happened to you? Why did you change? I said oh my god, that's the side effects."

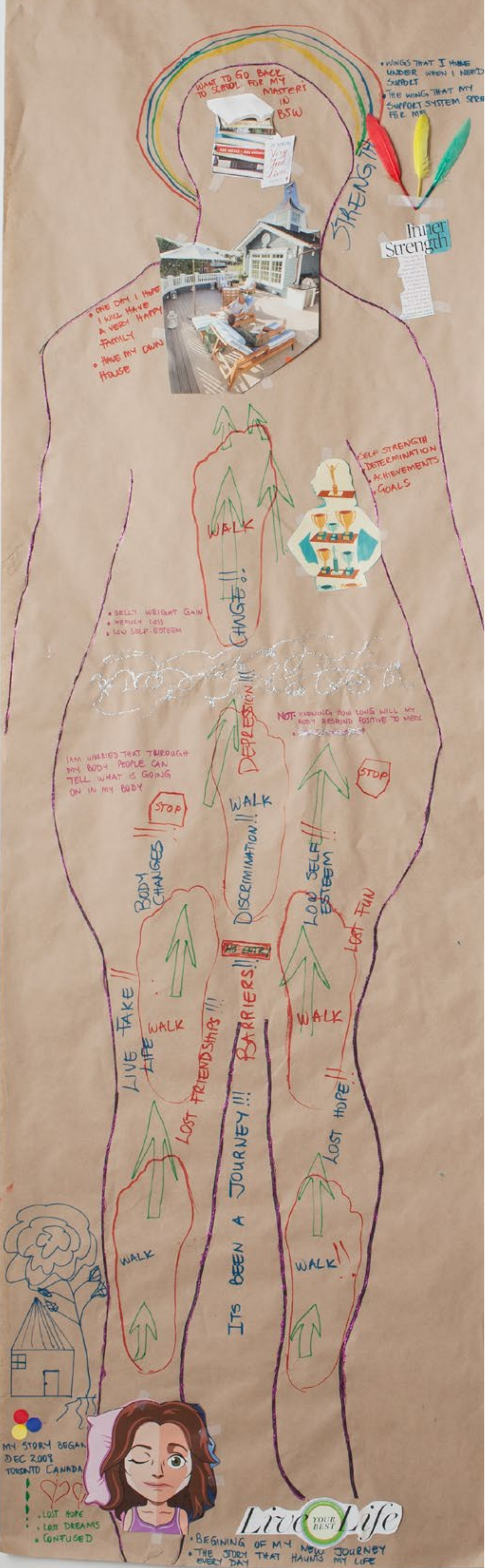


1) Feeling better today
2) have problems in sleeping
3) my dreams
(a) set up a business back home
(b) Helping less fortunate in my family
(4) wishing that there will be a cure for hiv.

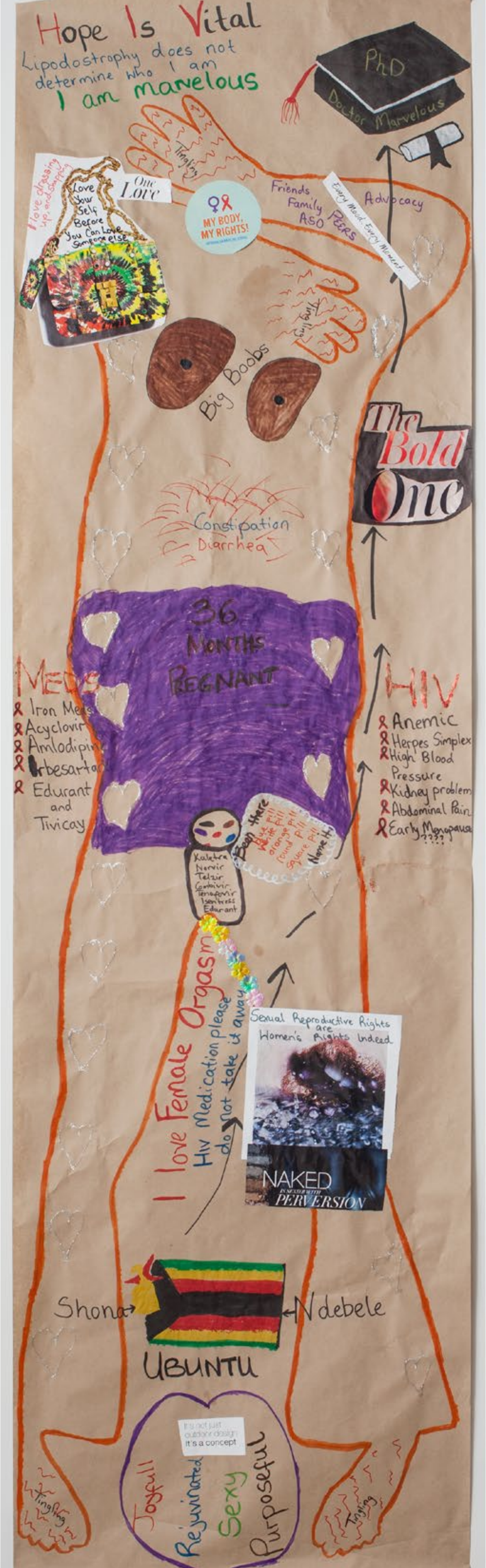
"This is not the end of everything, although we had a lot of things, side effects and medication and whatever. We have to live with it so anyway, I don't like my pot, that is one of the side effects, I'm also diabetic so I'm trying to beat HIV and diabetes which is not easy. Otherwise, we take one thing at the time"



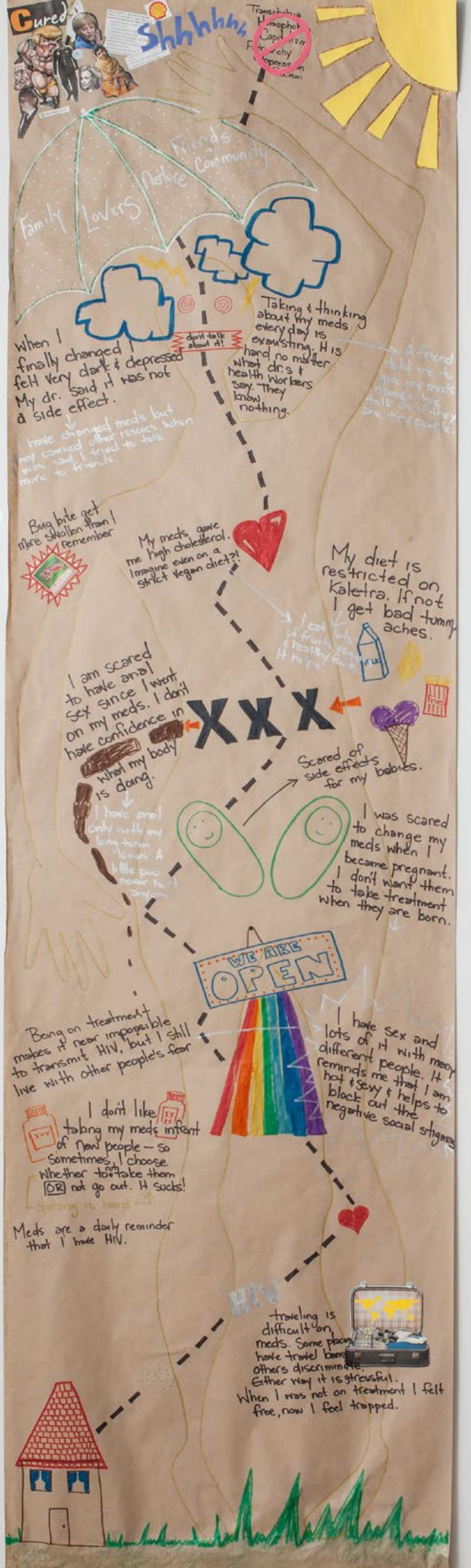
"Side effects, sometimes I don't know the difference between being normally sick or, if it's HIV. We need more information because we don't know when are we normal or not."



"My worries, I have like a lot of worries, if you see my body map, it has the curves. Growing hope as a child I never had that. Even now when I send pictures to my sisters, my young sister has simply said: "can you send a naked picture, because I don't believe those are your real hips". So these are my worries because I don't know how will this go, how will this go? Might end up and that, and I put the glitters on the belly because that's where my weight gain is showing a lot. My main worry is that, probably people might figure out that I'm talking medication even though I'm not telling them because my body is changing and I have no explanation to that. And my biggest worries, not knowing how long will the changes go."

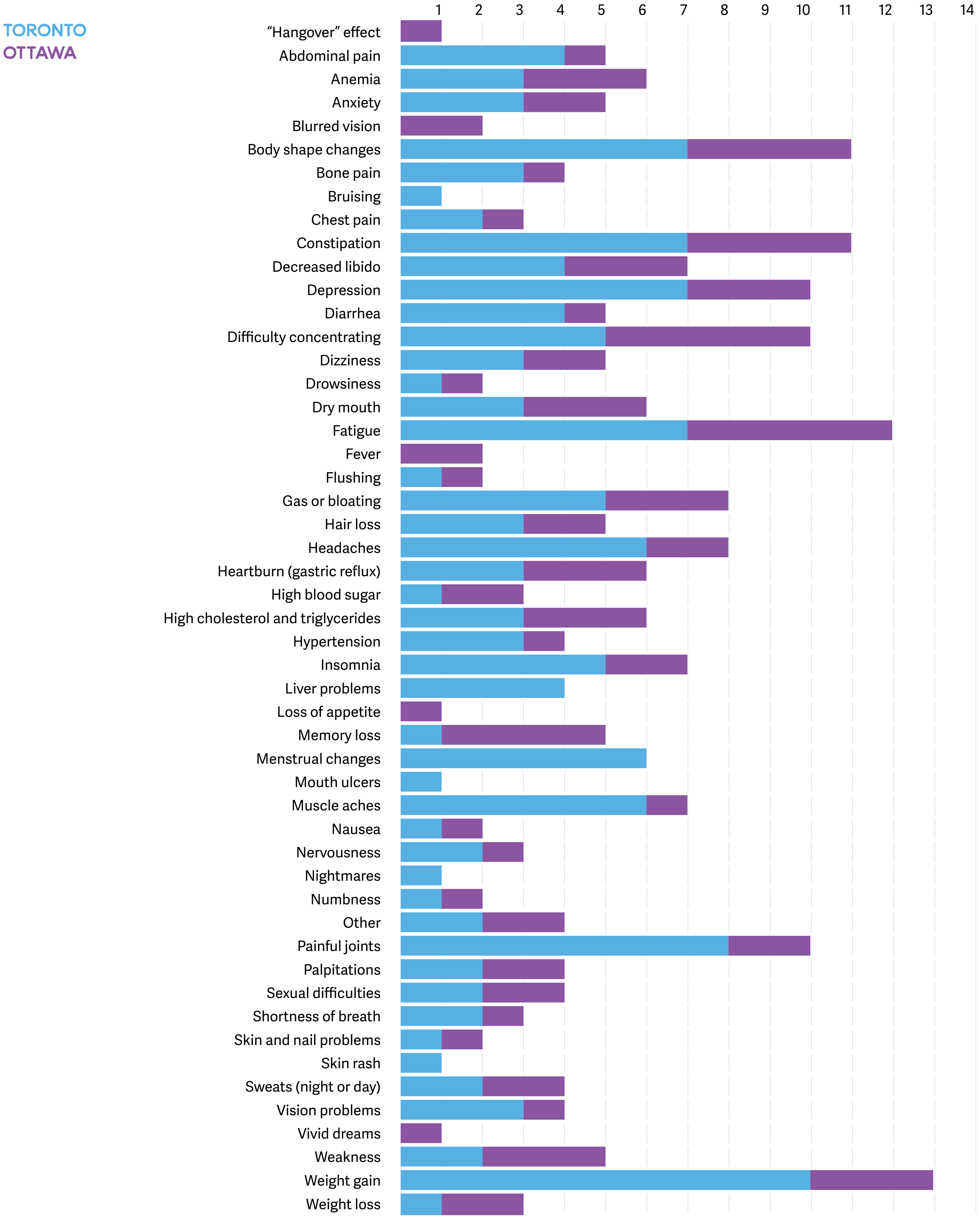


"For me something else that I find so annoying is for HIV positive people, every time when you go with something, you are told, even if they do test, a new test that I get, even an X-ray or whatever, they don't find anything. But you be feeling this pain, you'll be feeling all these pains, but they would check everything, there's nothing. So that's another big issue for me to say then how do get treated. And my fear is maybe something serious, maybe it's cancer, and then they find it when it's too late and my question always is: Is it the virus itself or is it the medication."



"When I was on Kaletra Kivexa, I had really high cholesterol, like dangerously high which is strange because I had a near vegan diet so, I didn't eat anything that would raise my cholesterol and they wanted to put me on lifetime cholesterol treatment which I was like 30 so that's a long time to be on cholesterol treatment. What else? So then I recently changed to Triumeq and that one well, I lost these things around my stomach and these side effects. I got a bunch of head stuff that started to happen. Like I felt like dark and depressed and I don't know like kind of these crazy eyes and my crazy eyes because I didn't know what was going on in my body and my mind and I would ask the doctor about it and the doctor was like: "that's not a side effect". But recently I've changed and it feels better. Also Triumeq was kind of scary because I recently found out I was pregnant and the idea of taking HIV medication and pregnancy is like what will the treatment, what will the side effects be on the babies, babies because there was two."

SIDE EFFECTS REPORTED BY WOMEN INCLUDED:



NEXT STEPS

> *I usually wright a bunch of questions before I go to my appointment and I make sure that some of them are answered if he has time. So I talk to him like it's a two way thing and if I know my, and I said: I know my body better. Because if I feel, you know, I'm having headaches and my doctor keeps telling me there's nothing wrong with me, then I need to continue convincing him there's something wrong with me and I need to get checked. So don't just, I don't just take you know, his word for you know, for it I know how I'm feeling, I don't know if I make sense. Yeah I know how I'm feeling so I advocate for myself*
>
> *My body, my rights, yes*

The workshops were particularly helpful to gather information on the needs of women and identify what the next step should be.

RESEARCH

Full inclusion of women (including transwomen) in research aimed at developing new antiretroviral drugs and understanding the side effects of current antiretroviral drugs. More research on the "real life" impact of antiretroviral drugs focused on side effects and interactions with age, gender, hormones, other medications, HIV, nutrition, and pregnancy

CARE

Greater access to and use of plasma concentration analysis for women who report side effects (i.e., analysis of the levels of drugs in the blood to detect toxicity levels). Improved care and support for women who report side effects including improved education, prevention, evaluation, recognition, management, and follow-up.

SUPPORT

Increased support for women who experience side effects at the level of the community, including support from women living with HIV, peer workers, and social workers who can work to ensure access to healthy food, affordable housing, social assistance, and programs that covers the costs of supplements, medications, and care. Increased support is also needed for women who experience body changes, intensified stigma, and fear/risk of disclosure.

COMMUNITY

Supporting women to share their experiences with others and share their knowledge of side effects (and ways of dealing with them) using community projects.

SUGGESTED CITATION: Gagnon, M., Logie, C. & Whitbread, J. (2017). My Body, My Story: Body Mapping and HIV Treatment Side Effects Project Report. Ottawa, CANADA.

RESEARCHERS: Marilou Gagnon, RN, PhD (Associate Professor in Nursing at the University of Ottawa), Carmen Logie, MSW, PhD, (Assistant Professor in Social Work at the University of Toronto), and Jessica Whitbread, MES (ICW Community Relations and Mobilization Manager).

CONTACT: For more information, please contact Marilou Gagnon, RN, PhD at marilou.gagnon@uottawa.ca.

FUNDING: This project was funded by the Women's College Hospital (Women's Xchange program).

ETHICS: This project was approved by the Office of Research Ethics and Integrity at the University of Ottawa (H02-16-03).

DESIGN: pulp&pixel – www.pulpandpixel.ca

WOMEN'S COLLEGE HOSPITAL
women's xchange

uOttawa

UNIVERSITY OF
TORONTO

ICW
INTERNATIONAL COMMUNITY OF
WOMEN LIVING WITH HIV