

SHAWNA Expert Community Consultations

Since our first team planning meeting in April 2014 with researchers, community and policy partners, the SHAWNA team has been busy hosting expert individual and group consultations to learn what HIV care and sexual health priorities are for women living with HIV, HIV service providers and other research and policy experts. GSHI and PWN hosted a number of expert consultations with women living with HIV (thanks to PWN for facilitating!). We have also had incredible input from staff of Oak Tree Clinic, IDC, PWN, YouthCO AIDS Society, BCCDC, Aboriginal Health Research Program (of UVIC), and Canadian HIV/AIDS Legal Network.

We are excited for further consultations planned this fall – *if we haven't heard from you yet, please do get in touch at shawna@cfenet.ubc.ca.*

We sincerely thank everyone who has participated so far in informing SHAWNA Project planning. Your openness and participation in identifying research priorities for and by women living with HIV has been critical to informing what questions SHAWNA needs to be asking. We are planning to launch in January 2015!

Priorities for Women Living With HIV

One-to-One Support: Many WLWH we consulted with identified that navigating the complex health care system is a daunting challenge. Access to a knowledgeable person (potentially a peer) who can provide support with booking & attending appointments, advocacy with service providers, understanding important health or medication information as well as counselling or crisis support could be an important way to improve women's health.

HIV-Related Stigma: Women in consultations identified that access to health care, social supports and housing are all affected by negative stereotypes and discrimination from care providers. WLWH also reported avoiding certain services due to fear of being 'outed' when accessing those services.

Focus on WLWH: While there are HIV-specific services and women-specific services available, neither of these completely addresses the health and social support needs of WLWH.

HIV Disclosure: There is a serious lack of support and information available for WLWH with regards to when and how to disclose their diagnosis with others. Some WLWH reported that their health care providers were unable to answer their questions about the legal implications of disclosure/non-disclosure and there were no clear resources for them to turn to for reliable and up-to-date information about this emerging issue.

Sexual Health: WLWH we consulted with reported difficulty accessing sexual and reproductive health care. HIV care providers tend to focus on HIV, and women-focused care including Paps and screening mammography can be challenging to access, in particular for women with transportation or mobility concerns.

Mental Health: For many WLWH, depression and anxiety are issues for which they have little to no support. Many participants felt that access to counseling, psychiatrists, and support groups for WLWH needs to be expanded.

Integrated Care: We heard from WLWH that communication among health and social care providers has not always been effective, which at times has resulted in lost opportunities for housing or enhanced care. WLWH expressed that for them, true integration of care goes beyond simple referrals to true collaboration between providers.

Employment and Education: There is not enough focus on supporting positive women who would like to work again or access professional training.

Food Security: Access to nutritious food has become increasingly difficult for WLWH. Generally food banks provide dried and canned goods but not enough fresh foods such as vegetables, dairy, or healthy protein sources. For some women transportation to and from food banks is also a barrier to accessing food.

Housing: Women agreed that accessing safe, secure and long-term housing continues to be a challenge. There are long waitlists that can take years to get through and it's easy to get "lost in the system."

Priorities identified by HIV Service Providers & Policy Experts

- Women-centred HIV care models
- Concerns of surveillance of WLWH in targeted outreach approaches
- Integrated sexual and reproductive health and allied health services
- Immigration and refugee health needs, cultural-sensitivity and diversity
- Criminalization of HIV non-disclosure and challenges for accessing care safely
- Transitions from youth to adult services
- Women's broader reproductive health, including aging and menopause, positive sexual and reproductive wants/rights/needs for WLWH



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