

# Women-Centred HIV Care Hub

## Community Member Payment Policy

Last reviewed and revised April 2024

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\*Terms explained in Appendix A are underlined the first time they are mentioned.

### Introduction

#### Policy Overview

The goal of this document is to clearly outline the approach the Women-Centred HIV Care (WCHC) Hub will take in ensuring community members are compensated fairly for their knowledge, experience, and work in carrying out the hub’s activities.

#### What is the Women-Centred HIV Care (WCHC) Hub?

The WCHC Hub brings together diverse stakeholders and experts in the field of women and HIV including clinicians, community-based organizations, allied health professionals, women living with HIV, policymakers, researchers, and learners. Funded for 4-years by The Canadian Institutes of Health Research (CIHR) in 2023, it represents a national coordinated and collaborative effort to broaden the reach of and strengthen knowledge mobilization of the WCHC Model across Canada. This has the aim of enhancing health outcomes, eliminating gaps in access to care, and improving the quality of healthcare for women with HIV as well as building capacity of women’s health researchers in Canada.

The hub’s overall vision is to create a feminist network environment that challenges misogyny and patriarchy to allow all people involved to reach their full potential via appropriately gendered care, knowledge mobilization (KM), and learning.

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#### Who is this policy for?

This policy applies to all people engaged with the WCHC Hub who:

- Identify as a person living with HIV;
- Have been invited to join the WCHC Hub in the capacity as a community member representing themselves;
- Are not taking part in hub activities as part of a pre-existing employment arrangement (e.g. a clinic, AIDS service organization [ASO], etc.).

In the following exceptional cases, people who are taking part in hub activities in the capacity of their role in an organization may be offered payment if:

- Their paid employment is unrelated to the activity being asked of them by the hub team and;
- They intend to carry out the tasks for the hub in their free time (for example, by using vacation days or time outside their normally scheduled hours that will not be flexed from usual hour banks).

In these circumstances, payment may be offered, providing the other criteria above are met and the individual signs a declaration stating so.

Throughout this policy, we utilize the term “community member” to refer to people living with HIV who are engaged in the hub’s activities. Other synonymous words include “peer”, “community research associate”, “community researcher”, “community consultant”, “person with living and lived experience”, “woman/gender-diverse person living with HIV”, “peer research associate” and more.

#### Why do we need this policy?

Women and gender-diverse people living with HIV are at the heart of all the hub’s activities. They are crucial members and leaders within the WCHC Hub team. However, we recognize that many individuals who will be involved in the hub as independent “consultants” are not paid for their time through an organization or pre-existing job (e.g. working at an ASO). Therefore, this policy exists to ensure that every person is compensated fairly and transparently for their efforts.

This policy was drafted in line with the frameworks and principles of the WCHC hub, namely:

- The GIPA principle and MEWA principle are important pillars in community-based HIV research. These principles recognize the rights of people living with HIV in research and programming concerning their lives. It includes the right to self-determination.
- The TCPS2 Chapter 9 principles are essential to consider when considering the involvement of Indigenous people and communities in community-based research. The principles include those of OCAP® and the equivalent Métis and Inuit principles, asserting that Indigenous people have control over data collection processes, and that they own and control how this information can be used. TCPS2 Chapter 9 also indicates that meaningful engagement with Indigenous people should be sought at the beginning of a project and maintained throughout, that the research

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should make a difference and help the community, and that the research preferentially be led by Indigenous people.

#### Will this policy change over time?

We recognize there is no “one-size-fits-all” model for community engagement and compensation. We anticipate this payment policy may evolve over the 4-year funding period. To ensure it stays up to date, the payment policy will be reviewed by the Women’s Community Leadership Team (WCLT) and Co-Principal Investigator group at least bi-annually.

#### Is the policy flexible?

Receiving monetary compensation for participation in the WCHC Hub activities may have an impact on financial benefits that a community member receives from other sources (e.g. payments from provincial disability or social assistance programs, private insurance, Canada Pension Plan, housing subsidies, etc.). See “Implications for Social Assistance and Taxes” for more information.

We are happy to work in collaboration with any community member who has concerns about hub payments interfering with their other financial sources. To discuss a plan, please contact the WCHC Hub Central Coordinator.

### Stipend rates and details

The WCHC Hub will use a quarterly (4 times per year) stipend format that will be paid through the schedule below. This means payment will take place once every 3 months.

The rates outlined below are based on consultation with the Women’s Community Leadership Team members, policies utilized in our previous projects, and similar existing payment guidelines (Appendix B). The rates reflect the differences, including difficulty and time commitment, which can and do exist in the tasks community members may carry out. Some of the activities below will be open to all Hub community members (e.g., the Women’s Community Leadership Meetings) and will occur regularly (e.g., 3-4 times a year). Other activities will be limited due to the scope of the work, timelines, and budgetary constraints.

When opportunities to participate are limited to a specific number of people, the WCHC Hub Central Coordinator (and/or sub-hub coordinator[s]) will reach out to community hub members to invite participation. The email will specify the expected activities, engagement, and time commitment as well as confirm the expected payment (based on the table below).

Generally, opportunities above the scope of the Hub and Sub-Hub meetings will be considered first-come-first-served. The call will be open for a specified amount of time (e.g., one week) to allow community members to fully consider the commitment and be in contact with the WCHC Hub Central Coordinator for further information if required. The following will be taken into consideration when calls for participation are shared:

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1. Community members' interest(s)/commitment(s) and locations will first be taken into consideration.
  - a. If an activity is related to one of the Sub-Hubs and/or working groups, community members on that sub-hub/working group will first be contacted.
  - b. If the activity requires in-person engagement (e.g., a presentation), local community members who are familiar with the local context, community interests/needs, and resources will have priority.
2. When opportunities arise that may be of interest to multiple community members and the activity is relevant and accessible (e.g., not limited to a specific region), the details of the activity and expected commitments will be shared with all community hub, sub-hub, or working group members (as applicable).
3. To ensure all community hub members are able to participate meaningfully and in the ways they wish, folks who have not yet participated in an activity outside of the regular meetings will be prioritized when they respond to an invitation. For example, if three people are interested in presenting the Women-Centred HIV Care Model and only one of these community members has not yet been able to participate in an additional paid opportunity from the Hub, this person will be prioritized.

The following table outlines some of the activities that are expected to occur throughout the grant. This table is not exhaustive, and stipend amounts that are made available for any additional opportunities (see table) will be agreed upon before the work takes place (noting that this may be negotiated if the work is wider in scope than anticipated).

| Activities   | Stipend amount   |
|--|--|
| <i>Regular Activities</i>  |  |
| Participation in meetings  | Hourly rate of \$27.50/hour for participation in the meeting |
| <i>Additional Opportunities</i>  |  |
| Consultations via teleconference   | Hourly rate of \$27.50/hour                                  |
| Sitting on interview panels (e.g. for Coordinators/Graduate Research Associates) | Hourly rate of \$27.50/hour                                  |
| Feedback on 1-4 page documents (e.g. abstract, infographic, lay summaries)       | \$27.50  |
| Feedback on 5-10 page documents (e.g., toolkits, grant proposals)                | \$55.00  |

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| Feedback on 1-25 presentation slides   | \$27.50  |
| Feedback on 26-50 presentation slides  | \$55.00  |
| Task-based collaboration and support (e.g., writing/creating knowledge translation materials, collaborating on/creating content for public sharing)  | \$27.50/hour or as agreed upon set rate for the task pursuant with industry standards (amount to be determined in advance of commitment) |
| Presenting on behalf of the Hub at a local and/or virtual event, as agreed upon by Hub (will range based on length of the presentation and requirements and will usually involve preparation meetings) | Typically \$150  |
| Presenting on behalf of the Hub at a conference, as agreed upon by Hub (note: travel stipend may also be applicable and will follow the applicable institution and/or provincial policies)             | \$210.00   |
| Conference Attendance (not presenting on behalf of the Hub)  | Volunteer  |
| <b>Attendance at weekly hub learning sessions</b> (e.g. Mentoring Future Leaders, Frameworks Values and Rights Talks, Navigating Academia Together, On AEHR Talks)                                     | Volunteer  |

| Quarter dates                 | Stipend amount submitted by coordinator for payment | Stipend typically received                      |
|-------------------------------|---|---|
| Q1 – January 1 to March 31    | Beginning of April                                  | Within 3-4 weeks of coordinator submission date |
| Q2 – April 1 to June 30       | Beginning of July                                   |   |
| Q3 – July 1 to September 30   | Beginning of October                                |   |
| Q4 – October 1 to December 31 | Last day before holiday break                       |   |

NOTE: If one of the coordinator submission days noted above falls on a weekend, it will be submitted on the next business day.

After consultation with community members, this format was chosen for several reasons:

1. To ensure community members have a clear expectation of how much money they can expect per opportunity, and when;
2. To ensure community members are receiving adequate compensation for any work they complete in relation to the Hub;
3. To account for times when there may be competing priorities, and community members have more or less time to engage in Hub activities;

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4. To minimize administrative burden on the research coordinator(s) by removing the need to submit individual requisitions each month.

#### **Community Member Terms**

This grant is funded for 4 years (2023-2027) with the possibility for extension pending future funding. Community members are welcome to join and leave at any time, and they can accept and/or decline any opportunity that is made available. For more information, please see the Women's Community Leadership Team Terms of Reference document.

#### **How are the payments determined?**

Throughout each quarter, the WCHC Hub Central Coordinator will keep track of meeting attendance and tasks for each community member. A few weeks before the end of each quarter, the coordinator will use this information to determine the payment for each CRA. The amount will be communicated to each community member via email. If community members strongly disagree with the determined amount, they are encouraged to contact the WCHC Hub Central Coordinator as soon as possible so an agreement can be reached.

#### **What if someone joins/leaves part way through an activity?**

If a community member needs to join/leave an activity before it is complete, the rate will be pro-rated based on completed work. For instance, if they agreed to create a presentation and co-present it but circumstances change and they are unable to co-present, they will still be paid for their work in preparing the presentation. In these cases, the WCHC Hub Central Coordinator will discuss individual circumstances with the community member ahead of payment.

#### **What activities are paid vs unpaid?**

We recognize that community members may choose to participate in the WCHC Hub for many different reasons including: working with peers, learning new skills, gaining specific experience, meeting new people, serving the community and more. It is a community member's choice to take part in the meetings, tasks, or other activities they are invited to work on and whether or not they accept any payment that is offered. While we ensure monetary compensation is offered to all community members involved in the hub for specific activities, there are some activities that we are unable to provide funding for. We also offer other, non-monetary benefits like access to regular trainings, support in developing CVs, or access to references for future employment. We are also open to discussing other ways our research team can support community members in their own professional development pursuits and/or knowledge translation efforts that could help them and/or their community.

The table above shows which activities are paid and which are volunteer.

#### **What about conferences?**

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In academic research, conferences are a vital part of networking, sharing results and building community with others.

The WCHC hub strongly encourages the participation of team members at conferences, research days and other research forums. We support team members in using WCHC Hub data and analyses to submit for conference abstracts and can provide personnel in-kind assistance in doing so if required. Unfortunately, we currently do not have the operating budget to contribute to the cost of the attendance of conferences (e.g. flights, registration, accommodation, food) for WCHC Hub members who are not asked by the Hub team to present or co-present. The WCHC Hub encourages team members to apply for conference scholarships to assist with conference attendance expenses, even if they are requested to present or co-present. A hub coordinator and/or principal investigator can help community members with applications and write a letter to assist with scholarship applications if required. Community members are asked to contact the WCHC Hub Central Coordinator for assistance identifying potential scholarship opportunities at least 3 weeks before the deadline.

#### Payment process

##### **Payment for central hub activities (attending overall hub meetings, Women's Community Leadership Team meetings, and participating in any Women's Community Leadership Team-related tasks)**

Central WCHC Hub funds are held at Women's College Hospital in Toronto, ON. For any central hub activities (as listed above), quarterly stipends will be paid from Women's College as per this payment policy. Payment will usually be made directly into a community member's bank account within 3-4 weeks of the end of the quarter, through an electronic transfer system. The WCHC Hub Central Coordinator will work with community members to obtain banking information, including a void cheque ahead of the payment date.

##### **Payment for sub-hub related activities (attending sub-hub meetings and participating in any sub-hub-related tasks)**

Each sub-hub has their own funding for community engagement. Thus, meetings and tasks done as part of a sub-hub will be paid from that sub-hub's funding which is often held at an institution other than Women's College Hospital. Sub-hubs are encouraged to determine a payment policy that works best for their team and are free to use this policy. It is likely that the sub-hub institutions will need banking information from community members similar to what was needed for Women's College Hospital.

#### Implications for social assistance and taxes

##### **Social Assistance**

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If a community member is receiving social assistance benefits (e.g. disability payments) there may be requirements that they not make over a certain amount of money per year. Community members are urged to review these restrictions before they agree to activities on the WCHC Hub and/or their compensation.

#### Tax Requirements

At the time this policy was prepared, the Canada Revenue Agency requires the collection of a SIN and the issuing of a T4A if a community member earns more than \$500 annually. Therefore, when setting up payment, a community member will be asked for their SIN. If a community member has concerns about giving their SIN, they can discuss their concerns with the WCHC Hub Central Coordinator.

## Appendix A: Definitions of key terms

**Canadian Institutes of Health Research (CIHR)** – A federal agency responsible for funding health and medical research in Canada.

**Community Research Associate (CRA)** – Sometimes referred to as a “Peer Research Associate”, a CRA is a woman living with HIV who is meaningfully involved in research activities and projects, like the WCHC Hub. They are paid for their work on various research tasks which can range from conducting interviews to reviewing documents and doing presentations depending on the project.

**Co-Principal Investigator (Co-PI) Group** – A group of leaders from across Canada who oversee all activities of the WCHC hub and are recognized as principal investigators by CIHR. This group includes women living with HIV, researchers, clinicians, and other service providers who are experts in women-centred HIV care.

**Engagement Level** – A system created to determine what stipend category a community member’s work belongs to. Engagement levels differ in the amount of work and time spent doing activities related to the WCHC hub and have different stipend amounts associated with them.

**Greater Involvement of People Living with HIV and/or AIDS (GIPA)** – A principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination, and participation in decision-making processes that affect their lives. The GIPA principle was formalized by 42 countries at the 1994 Paris AIDS Summit, following years of activism by people living with HIV who advocated for their personal experiences to shape the AIDS response. By 2001, 189 UN member countries endorsed the GIPA principle. GIPA also contributes to the fight against stigma by eroding false binaries of service providers (thought to be those living without HIV) and service users (those living with HIV) and breaks down fears and prejudices as people living with HIV are viewed as knowledge holders.

**Knowledge Mobilization (KM)** – an umbrella term encompassing a wide range of activities relating to the process of facilitating the uptake of research results in care, policy, and programming.



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Knowledge mobilization is relational to ensure that knowledge is transformed into formats that are accessible and useful to a broad range of knowledge users.

**Meaningful Engagement of Women Living with HIV and/or AIDS (MEWA)** – A key feature of women-centred HIV care that was coined in response to the lack of gender analysis in the GIPA principle and the significant barriers to meaningful involvement in the design/delivery of HIV services faced by women living with HIV. MEWA recognizes the right of women living with HIV and other affected populations to participate as active and equal agents of change in their own health.

**Ownership, Control, Access & Possession (OCAP®) Principles** – The First Nations principles of ownership, control, access, and possession – more commonly known as OCAP® – assert that First Nations have control over data collection processes, and that they own and control how this information can be used.

**Peer/Community Member** – In this context, a person living with HIV. Often, peers provide support, information, and/or leadership to others in the HIV community. Some people prefer the term “community member” to “peer”, as often the word “peer” discloses a person’s HIV status.

**Self-determination** – In the context of the HIV community, self-determination refers to the empowerment and autonomy of individuals and communities affected by HIV to make decisions about their healthcare, treatment, and overall well-being. It recognizes the importance of respecting the rights and preferences of people living with HIV.

**Social Assistance** – Payments made by the government to assist individuals financially. There are many different forms of social assistance one may be accessing. These financial assistance programs need to be applied for from the government and once granted, certain conditions need to be met.

**Social Insurance Number (SIN)** – A nine-digit identification number used in Canada for various government programs and services, particularly related to taxes, employment, and benefits.

**Stipend** – A fixed, regular payment typically paid on a periodic basis (e.g. monthly or annually). Stipends are usually associated with specific activities and paid to someone for their work on these activities.

**Sub-hub** – In recognizing the diversity of women living with HIV in Canada, the WCHC Hub has developed several “sub-hubs” which will focus on regional or population specific work. These include sub-hubs in British Columbia, Ontario, Manitoba, Alberta & Saskatchewan, as well as sub-hubs focusing on African, Caribbean & Black Women, Indigenous Women, and Trans/Gender Diverse People. Community members are invited to serve on multiple sub-hubs based on their identity, experiences, and expertise.

**T4** – A document that summarizes all of the money paid by an employer to an employee during a calendar year. Most employers provide a T4 to employees around February for income earned in the previous year.

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**Women-Centred HIV Care Hub** – The WCHC Hub is a virtual group of diverse stakeholders and experts in the field of women and HIV including clinicians, community-based organizations, allied health professionals, women living with HIV, policymakers, researchers, and learners. It was created through funding from the Canadian Institutes of Health Research.

**Women-Centred HIV Care** – A model of care focused on care and support for and with women living with HIV that is informed by the unique barriers that they face in accessing and engaging in care. It requires a specialized and integrated approach that focuses on women's specific needs such as trauma- and violence-aware care, women's health care, and peer support, leadership, and capacity building.

**Women's Community Leadership Team (WCLT)** – At the center of the WCHC Hub, the Women's Community Leadership Team includes community members from across Canada. This group meets regularly to ensure the hub is prioritizing leadership, priorities and needs of women living with HIV. For more information, see the Women's Community Leadership Team Terms of Reference document.

## Appendix B: References

The following documents were consulted when drafting this policy:

INVOLVE, National Institutes for Health Research. *Policy on payment of fees and expenses for members of the public actively involved with INVOLVE*. 2016. <https://www.invo.org.uk/wp-content/uploads/2016/05/INVOLVE-internal-payment-policy-2016-final-1.pdf>

Greer, AM & Buxton, JA in partnership with the Paying Peers Working Group. *A guide for paying peer research assistants*. UBC & CDC BC Center for Disease Control. 2016. <https://paninbc.ca/wp-content/uploads/2016/05/A-guide-for-paying-peer-research-assistants-challenges-and-opportunities.pdf>