

# Let's Talk Self Advocacy:

## Navigating Mpox Care

For many gay, bisexual, and queer men—including Two-Spirit, trans, and gender diverse people (2S/GBTQ+), mpox has caused stress and confusion in our lives. As outbreaks have developed, it hasn't always been clear what steps to take, or how to navigate medical care. It can be tough to speak up for our needs in healthcare settings, especially when they relate to our identities as 2S/GBTQ+ people. This resource will give you an idea of what to expect when navigating health care for mpox, and how to advocate for yourself along the way.



*"It was frustrating when I had mpox, trying to advocate for myself to access health information in a setting that didn't seem to have it. But sometimes it's important to stand up and keep fighting for the information and care you need." - John*

**Know what you're looking for?** Here are some shortcuts to help guide you through these resources:

### [What To Expect when navigating mpox care](#)

- [Testing and diagnosis](#)
- [Contact tracing](#)
- [Pain management](#)

### [What if I don't have provincial insurance?](#)

- [I am an international student](#)
- [I am a refugee/asylum claimant](#)

### [Mental health and stigma](#)

### [Patient's rights](#)




## What To Expect when navigating mpox care

While some people have positive experiences receiving care for mpox, you may find your health care provider is uncertain or unaware of how best to provide support around mpox.

Queer people's experiences with the medical system also vary significantly. For example, those of us in rural or remote communities may have a harder time accessing testing and other supports. Those of us who experience barriers to culturally competent health care—including Indigenous, and immigrant 2S/GBTQ+ people—may experience similar barriers when accessing care for mpox.

If you know a healthcare provider you trust, you may want to reach out to them for support as you engage with testing, treatment and care for mpox. You may also find it helpful to draw on the information and self-advocacy tips included here.

### **General tips for self advocacy with health care providers:**

- Come early
  - Take notes
  - Think about questions or any issues you may want to raise beforehand
  - If there's anything that seems unclear or complicated, ask them to explain.
- 



## Testing and Diagnosis



### **What does testing involve:**

- Typically a health care provider will test for mpox by swabbing one or multiple sores (pocks). If you don't have sores, it may be possible to do a throat swab instead; however sores have a higher viral load, meaning it is easier to identify mpox using that method. In some cases, testing may require having blood drawn as well.
- The preferred testing method for mpox is a Polymerase Chain Reaction (PCR) test. Your sample will be sent to the National Microbiology Laboratory and may take 3-4 days to process.

### **Self advocacy tips:**

- If you have a rash, your healthcare provider may think you have syphilis or herpes. If your rash seems like pocks, or if you believe your rash is mpox and not syphilis, insist on receiving a mpox virus test. Most places that can test for syphilis can test for mpox.
  - Healthcare providers may be reluctant to provide you with a test if you do not have visible symptoms. Some healthcare providers might make the mistake of assuming that a lack of symptoms indicates no need to test.
  - When seeking testing for mpox, your healthcare provider may encourage you to test for STIs, including HIV. It is your decision whether or not to proceed with these tests.
  - If you have been notified that you were a contact for mpox, try to mention this when you request a test.
- 
- 

***There is unfortunately not universal availability of testing throughout the country. Here are some examples of what is being offered in some regions, as of October 2022:***

- In Alberta, tests for Mpox are available at many sexual health clinics. Tests are generally only being offered to those presenting symptoms.
- In Saskatchewan, Manitoba, and the Atlantic provinces, public health agencies recommend you call 811 to find where mpox tests are available.
- Anywhere in Ontario that can test for syphilis can also test for mpox<sup>1</sup>.
- In Quebec, tests are being offered to those presenting symptoms, including lesions if you have had sexual contact with a man within 21 days of symptoms appearing. Tests are also being offered to those involved in sex work<sup>2</sup>.
- In BC, you can find testing at Primary Care or Urgent Primary Care Centres (UPCCs), and STI Testing and Treatment Clinics. In more rural locations you may have to visit a walk-in clinic or your nearest emergency room<sup>3</sup>.

## Contact Tracing

### ***What does contact tracing involve?***

- If your test for mpox comes back positive, you may be asked by health-care providers to identify your recent sexual contacts, or other close contacts (likely within the last 21 days). This is to inform them of potential exposure to mpox. These individuals can be contacted anonymously in most cases by the public health team.
- As part of this process, the health care provider or public health officer may ask very detailed and personal information about your sex life.

### ***Self advocacy tips:***

- Contact tracing may be a time-consuming, uncomfortable, and invasive process. Health care providers may be very eager to get this information. It is completely valid to take a break during this conversation if you're feeling overwhelmed. You can also ask them to have this conversation at a later date when you are ready.
- While contact tracing can help inform folks who may need to get tested, you are under no obligation to provide information about your sexual or social contacts if you do not wish to. It's also common during sexual health contact tracing for folks to report anonymous partners if no contact info was exchanged.

### ***So I tested positive for mpox....***

If you tested positive for mpox, you aren't alone. It takes courage to get tested, and hey—now you know! You will most likely have to self isolate for at least 2 weeks. This time may be difficult, but remember that mpox isn't your fault.

In testing positive for mpox, you're following in the footsteps of thousands of 2S/GBTQ+ people and others who happen to have gotten mpox and made it through the other side.

If there are friends, (chosen) family or community members you can rely on, you may want to reach out for support. These people can help you coordinate things like food or supply delivery, or provide emotional support while you isolate.

### ***Mpox is a "reportable disease" - What does this mean?***

Mpox is a reportable disease like many other communicable viruses. This means that public health will anonymously be notified that a new case has been identified. This is not tied to any information that can identify you.

<sup>1</sup>[GMSH, Monkeypox "What we know"](#)

<sup>2</sup><https://www.ciusss-capitalnationale.gouv.qc.ca/sante-publique/maladies-infectieuses/varirole-simienne>

<sup>3</sup><https://checkhimout.ca/wp-content/uploads/2022/08/Mpox-WTF-Community-Member-Guidance.pdf>



## Pain Management

### ***How is pain managed for mpox?***

- In many cases, people with mpox aren't receiving much when it comes to pain management. Your health care provider might tell you to take over-the-counter pain medications, like Advil or Tylenol.
- In some cases, health care providers are prescribing stronger pain medications to help with mpox recovery. This decision is up to the individual prescriber.

### ***Self advocacy tips:***

- Your health care provider is probably not used to treating this kind of infection. Health care workers are also receiving little guidance on pain management for mpox. If you are in severe pain, make sure they know to what extent this pain is impacting your life—for example, if it is impacting your ability to eat, sleep, or go about your day.
- Your needs regarding pain management may change. Don't be afraid to contact your health care provider if this occurs, and let them know you may need additional or changing support to manage your pain.

### ***Other tips to reduce pain from mpox:***

- If you have lesions in your rectum, a stool softener may help ease the pain of using the bathroom. Vaseline can also be helpful.
- If your pain is interfering with your regular sleep, consider using sleep aids which you are comfortable with. You might want to employ any pain management or pain coping strategies that you are comfortable with to lessen the intensity of the pain.

## What if I don't have provincial insurance?

You may be able to access certain services without provincial insurance. If there is a health care provider you trust, they might be able to support you and provide more information. For example, if you are in Ontario you can access certain services without OHIP at Community Access Care Centres. To find one near you, [check out this link](#).

### ***I am an international student***

Most schools require students to apply for provincial health insurance. This coverage usually begins 3-4 months after the beginning of your program date. If you did pay for provincial insurance, this would have been as part of your student fees.



If you are currently a student at a post-secondary institution, you may be able to access care through your university's sexual health clinic or hospital. Vaccine clinics may also be offered at your campus. In many cases, you will not be asked to provide a Provincial Health Number for these services.

Some universities may also offer housing options for those needing to isolate who live on campus. Contact your residence office if you are in this situation.

### ***I am a refugee/asylum claimant***

In most provinces, you will be eligible to apply to provincial Health insurance (AHSIP, MSP, OHIP, etc) with a Confirmation of Permanent Resident document or a Permanent Resident Card issued by Immigration, Refugee and Citizenship Canada (IRCC). If you are still waiting on this, you may be covered under the Interim Federal Health Program (IFHP) while you wait for provincial coverage. If you are still waiting for a decision on your asylum claim, you are also eligible for IFHP. You can apply for [IFHP coverage here](#).

There may also be specific services you can draw on in your area. For example, if you are an asylum claimant/refugee living in Ontario, you can call the Refugee HealthLine -- 1-866-286-4770 - to be connected to a healthcare provider.



# Mental Health and Stigma

Stigma harms us all by contributing to the marginalization of our communities and our needs.

Folks who have experienced mpox have also shared how stigma from our own community can act as a barrier to access testing or treatment, may worsen the loneliness of isolation, and may leave folks with feelings of shame after their recovery.

For many, experiences of loneliness and distress during isolation can be severe, especially for those isolating alone or with precarious employment. Remember that you are resilient and that Mpox is temporary. Be kind to yourself. Listen to your own needs and feelings.

## ***Tips for self isolation and mental health***

- You might find it helpful to try and create some new routines during isolation. Some folks isolating have engaged in journaling, gardening, art, and other at-home activities they may have not previously had time for.
- Try reaching out to people you trust for support. Have friends check-in on you when you can.

## ***How can we reduce stigma?***

- Now is the time to check our words, actions, and beliefs; and whether what we're expressing is helping or stigmatizing folks affected by mpox. This is also an opportunity for us to show up for friends and community members who may be in need of support.

# Patient's Rights

Accessing care for mpox can be daunting, but you deserve to be treated with dignity and respect throughout the process. As a patient, you also have certain legally protected rights. These include:

- The right to be informed of all treatment options.
- The right to privacy
- The right to care regardless of who you are.
- The right to full information/understanding what any diagnoses may mean for you.
- The right to understand any decision on care before moving forward.
- The right to refuse care, or to change your decision about care at a later date.

In most contexts, treatment must only be given when patients give free and informed consent; to obtain consent your healthcare provider must inform you of:

- What your illness or health condition is (what they have diagnosed you with),
- What treatment or health care they suggest,
- How the treatment may help you (what the benefits are),
- What the risks of the treatment are, and
- What other treatment options there are (including not getting any treatment).

If you feel that any healthcare professional or staff have treated you in a way which violates these rights, including discrimination, you can file a complaint with your province's human rights tribunal.