#MyDataOurHealth

MP Engagement Toolkit









Your data, their rules... Unless you speak up!



We all generate health data, when we register for a vaccine, get an STI test, use a period tracking app, access telemedicine, or even wear a fitness tracker. But do you know where that data goes, who has access to it, and how it's used?

In many cases, health data is collected, shared, or even leaked without our consent. People have faced stigma, discrimination, denial of services, and even violations of their rights because of how their health data was mishandled! And often, those most affected are the least likely to have a say.



Why it matters?

Health data can influence decisions about your healthcare, insurance, employment, or public benefits. Weak protections and a lack of transparency create real harm. But right now, most people are not even aware or are shut out of the decisions about how their data is governed.

If we don't demand strong rules, others will write them for us, and they may not have our best interests in mind!



What's the MyDataOurHealth campaign?

<u>My Data Our Health</u> is a global campaign to put people, especially youth, women, and marginalised communities, at the center of decisions about health data. We're pushing for governments to adopt better laws, based on the <u>Health Data Governance Principles</u> (HDG) and a <u>Model Law</u> designed to protect your rights.

We do this by sharing stories, mobilising action, and putting pressure on politicians, including Members of Parliament (MPs), to take a stand!

That's where you come in!

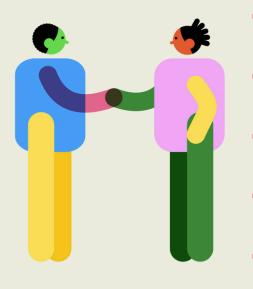


Generation Speak for You. Make Sure They Hear You.

Members of Parliament (MPs) are elected by the public to represent the people who live in their area (called 'constituents') in national decision-making. Their job is to listen to the concerns of the people they represent and bring those issues into the political space, like parliament. MPs play a key role in shaping and debating new laws, approving national budgets, scrutinising government decisions, and holding ministers accountable.

They can propose legislation, vote on policy changes, influence political priorities, and raise awareness of important issues through speeches, debates, or parliamentary questions.

Here's what MPs can do:



- Support action to strengthen national legislation governing how health data is collected and used (the <u>Model Law</u> can help with this).
- Call on the Ministry of Health to back a global resolution on health data governance at the World Health Assembly.
- **Raise the issue in parliament** through questions, debates, or motions - to make sure the government is taking action on this issue.
- Join as a health data governance Parliamentary Ambassador to champion reforms nationally and globally, including the Model Law to support this.
- Stand with youth and civil society by participating in campaign events, sharing content, and endorsing demands.

You don't need to be an issue expert or advocacy whiz to influence your MP. You just need to speak up!

Key products and links:

Campaign <u>Toolkit</u> Health Data Governance <u>Explainer Video</u> Health Data Governance Principles <u>Explainer PDF</u>

Where'sMyData? <u>Action</u>



How can you engage MPs?

Whether this is your first time taking action or you're already organising with others, here are concrete things you can do:

As an individual	 Send an email to your MP using our <u>template letter</u>. Make it personal. Tell them why this issue matters to you. Call their office. It's okay to be nervous, <u>our call script</u> will help. Ask for a meeting. You can do this by email or in person. MPs often respond well to respectful, informed constituents. <u>Use these key messages & tips on framing your message</u>. Attend an MP hosted event. MPs may hold events to meet their constituents; this is a nice informal way to chat to them about why this issue matters to you. Tag them on social media. Use #WheresMyData and @ them to make your message visible. Make a video about your experience trying to access your health data! Tag your MP Ask them to endorse the Model Law and commit to raising it in Parliament.
ln a group	 Host monthly meetups with friends, classmates or likeminded advocates, to take actions together. Co-write letters to MPs, letters to editors, or even a manifesto with your group. Doing it in a group can make it fun! Create a TikTok or Instagram series sharing personal stories. Or do 'street quiz' testing people's health data knowledge. And remember to tag your MPs. Lead a youth teach-in on data rights and the campaign. Plan a symbolic action around a national awareness day (e.g., wear a data-themed badge, host a digital flash mob, organize a parliamentary day where you set up a series of meetings with MPs, organize an MP 'Where's My Data? 'challenge', e.g. challenge your MPs take the action themselves & see first-hand the issue of health data governance & share their experience). Launch a podcast or live conversation featuring other advocates and supportive MPs.

MPs notice when their constituents are active, creative, and persistent. The more public the support, the more pressure they feel to act.



Tools and Resources

Use these tools to plan, act, and follow up with confidence.

Template Letterto Your MP

Make your message clear and compelling. We provide the structure you personalise it.

Call Script

A short guide to help you introduce yourself, explain the issue, and ask your MP to act.



Not sure what to say? Use our tested messages, campaign hashtags, and MP handles.



Simple text or email you can send to request a meeting.



Simple and straightforward messages to help you make your point!



Be respectful, stay focused, and lead with values.

Let's make it count

This isn't just a toolkit. It's an invitation. MPs are elected to represent you. And when they hear from enough people, they act. That's why this moment matters.

The way your health data is governed affects access, equity, and trust. By raising your voice and encouraging others to do the same, you can shift public pressure and drive political change. You don't need permission to start. You just need this toolkit, a few friends, and your voice.

Together, let's make our data our power.

Want more support or have a story to share? Contact campaigns@transformhealthcoalition.org