

Quarterly Action Update

This quarter's focus

Talk to your MP and ask: WHERE'S MY DATA?

Have you ever tracked your period? Registered for a vaccine? Been tested for HIV, TB or an STI? Had a telemedicine consultation? Used a health chatbot or symptom checker? Worn a smartwatch or fitness tracker? Or just went to your clinic for a check up? Then you've created health data. But do you know where that data is now? Who can access it? How is it being used, or possibly, misused?

Across the world, people's health data is being collected, and sometimes it is leaked, or shared in ways they never consented to:

- + In India, vaccine registration data was leaked and made searchable on Telegram.
- In Kenya, people living with HIV have had their health data around their status shared without consent, leading to stigma and exclusion.
- In the U.S., period tracking app data has been used to investigate abortion access. And mental health app data has been shared with third parties, and there are concerns that employers may access this data and discriminate in hiring people.
- In Brazil, COVID-19 test results, and patient records were exposed publicly through a government platform.
- 🔶 In Indonesia, hackers accessed national health insurance data of millions.
- In South Africa, HIV status has been disclosed through poorly controlled health systems, exposing people's privacy and putting them at risk.

And this isn't just about privacy. It's about safety, discrimination, rights and power. And in many countries, there are no clear laws or policies to protect all of us. That's why we need stronger legal protections. And that starts with Parliamentarians and YOU.

Why parliamentarians? They write the laws. And right now, those laws are not keeping up with how fast our health data is being collected, digitised, and shared. Parliamentarians can:

- 🔶 Pass national legislation to govern health data
- Demand transparency from governments and tech companies
- 🔶 Amplify the issue in public debate

But they won't act unless they hear from people like you.





How can you take action?

Ask one MP to care.

Whether it's a tweet, a message, or a face-to-face conversation reach out to your MP and ask:

"What are you doing to protect our health data?"

You don't need to be an expert. You just must ask the question.

3 simple ways to act:

1) Send a message to your MP

2) Tag your MP on social media

3) Host a 'Where'sMyData?' Conversation Use our sample message:

"Hi [MP Name], I'm concerned about how health data is being used. What are you doing to ensure people's rights are protected?"

Use #MyDataOurHealth + #LegislatorsForHealthData:

"I don't know where my health data is or who's using it. @[MP_handle], what are you doing to protect our rights?"

Ask your friends or followers:

Do you know where your health data goes? Could it be used against you? Post your reflections and tag your MP.

Join the campaign for International Day of Parliamentarianism. Tag us and share what you did. Use the #MyDataOurHealth and #MPsForHealthData

in @Transform Health

X@trans4m_health

@transformhealth.bsky.social

Tools that may help you:

MP Engagement <u>Toolkit</u>

Act by 30 June

Where'sMyData? <u>explainer</u> Health data governance advocacy <u>explainer</u>