

REMAKING THE MY HEALTH RECORDS (INFORMATION  
COMMISSIONER ENFORCEMENT POWERS) GUIDELINES

Office of the Australian Information Commissioner

20 February 2026



## About NAPWHA

Founded in 1989, the National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people with HIV. Through leadership in policy, health promotion, representation, education, and prevention, NAPWHA strives to minimise the adverse personal and social effects of HIV. By championing the participation of people living with HIV at all levels of the national response we aim to build a positive future for all in our communities.

NAPWHA strengthens the national response to the HIV epidemic by ensuring the meaningful involvement of all people with HIV and plays an active role in realising a partnership approach in all aspects of our response.

## Contact

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NAPWHA thanks the Office of the Australian Information Commissioner (“OAIC”) for the opportunity to respond to the draft *My Health Records (Information Commissioner Enforcement Powers) Guidelines 2026* (“Guidelines”).

This policy submission is presented on behalf of people with HIV in Australia, with a focus on how changes to the Guidelines can best accommodate the privacy needs of people with HIV.

### **1. Are the draft Guidelines clear, relevant and practical?**

While the streamlining and simplification of language in the draft Guidelines are welcome, the submission could further highlight that practical clarity must be viewed through the lens of diverse communities. People with HIV come from diverse backgrounds with varying levels of health, technological, and English literacy. The Guidelines should ensure that the processes for lodging complaints and understanding enforcement are accessible to those who may struggle with complex regulatory language.

### **2. Do the draft Guidelines sufficiently assist the participants in the MHR system in understanding their privacy obligations and how the Information Commissioner will generally approach enforcement issues in relation to the MHR system?**

Section 7 of the Guidelines outlines factors the Information Commissioner may take into account in deciding whether to take enforcement action against a person in relation to the My Health Record system and what action to take. NAPWHA generally supports the inclusion of 7.1(d)(i) so the Commissioner may take into account the risk of substantial harm to vulnerable people and groups when deciding on enforcement. NAPWHA would support the Guidelines going further in defining ‘vulnerable people and groups’ as people who experience higher rates of social stigma and discrimination, such as people with HIV and other blood-borne viruses, sex workers or people who use drugs. Additionally, the Guidelines could explicitly note social stigma, discrimination, and legal repercussions as examples of “substantial harm” that the Commissioner can have regards to.

NAPWHA urges OAIC to strengthen 7.1(d) by stating when the Information Commissioner ‘should’ or ‘must’ (as opposed to ‘may’) take into account the risk of substantial harm in deciding whether to take enforcement action. Unauthorised access to such sensitive health data for vulnerable groups can have life-altering consequences, including stigma, discrimination, the loss of employment, the jeopardising of parental custody, and the risk of criminalisation. In order to maintain the trust of people with HIV, the privacy framework must be perceived as appropriately recognising the ever-present threat of stigma and discrimination that positive people live with every day. Without adequate protections and compensation, it risks undermining the clinical trust between a patient and their healthcare provider.

Moreover, the Guidelines should emphasise that enforcement powers will be used to uphold the explicit informed consent model. Any act that bypasses a patient's choice to control which parts of their record are shared should be a primary focus for civil penalties or compliance notices.

### **3. Are there any matters that you believe the draft Guidelines should cover that have not been covered or should be covered in greater detail?**

While the *My Health Records Act 2012* makes the unauthorised access of information a crime, NAPWHA notes a critical deficiency in the current framework regarding victim compensation and accountability. There is no mechanism for people whose privacy has been breached to get compensation for negative consequences that flow from such a breach. While the Information Commissioner has the power to make determinations that include declarations for compensation for "injury to feelings or humiliation" under s 52 of the Privacy Act, this determination is not binding (1B) and, we submit, is insufficient to compensate for the extremely detrimental consequences that unauthorised disclosure of HIV status can occasion. The Guidelines should be enhanced to provide clearer instructions on how the Information Commissioner will use enforcement powers (such as determinations under Section 52 of the Privacy Act) to ensure that compensation is not just "available" in theory, but is accessible and commensurate with the severe social and legal damages that flow from the disclosure of sensitive health information.

### **4. Are there any other ways in which the draft Guidelines could be enhanced?**

NAPWHA advocates for a formalised role for people with HIV within the regulatory framework when considering breaches that impact people with HIV to ensure that enforcement actions are informed by a nuanced understanding of social harm. Under section 27(3) of the *Privacy Act 1988*, the Information Commissioner has the power to establish a "panel of persons with expertise" to assist in performing their functions. The Guidelines should explicitly note that when investigations involve sensitive health data or vulnerable populations, the Commissioner will draw upon such a panel with lived experience. NAPWHA submits that the presence of representative people with HIV on such a panel would help the Commissioner to effectively weigh the "risk of substantial harm" or "social stigma" (under section 7.1(d) of the Guidelines) in relation to HIV related disclosures.