An official website of the United States Government. 🇺🇸

Docket (/docket/CDC-2024-0020) / Document (CDC-2024-0020-0001) (/document/CDC-2024-0020-0001)
 / Comment

💬 **PUBLIC SUBMISSION**

Comment from Crow, Tonayo

Posted by the **Centers for Disease Control and Prevention** on Apr 6, 2024

View More Comments 2 (/document/CDC-2024-0020-0001/comment)

View Related Comments 2 (/docket/CDC-2024-0020/comments)   Share ▾

Comment

As a graduate student in public health studying public health law, I thought it would be worth analyzing Docket (CDC-2020-0020) through the lens of a Westinghouse test. Westinghouse sought to balance the privacy of employee medical records versus the regulatory power of NIOSH to collect health information for the sake of protecting occupational health and safety. For Docket (CDC–2020–0020), the test would go as follows:

1.   The type of record and the information it contains:
a.   Firefighters are asked to voluntarily submit: informed consent, a user profile, an enrollment questionnaire, and a records request. This means that the registry is collecting personal information and medical information.

2.   The potential for harm in any unauthorized disclosure:
a.   While the registry is deemed voluntary, were this information to be shared in a way that was personally identifiable, there could be harm to individual firefighters from a social and emotional perspective. If this information were shared beyond the necessary confines of the registry, firefighters may experience harm from the breach of trust that their information would be kept private.

3.   The injury from disclosure to the relationship in which the record was generated:
a.   The information is submitted voluntarily by firefighters, except for medical records which would be requested via primary care doctors/providers. Were a doctor to submit information without informed consent from their patient, there is potential harm to that doctor/patient relationship.

4.   The adequacy of safeguards to prevent non-consensual disclosure:
a.   Safeguards for this registry should include, at minimum, the following:
i.   Training people to handle sensitive information.
ii.   Providing access to data only as needed (e.g., top NIOSH and CDC officials should never see individualized data).

iii.   Using encryption and passwords to protect data on the registry.

iv.   De-identifying information for the purposes of reporting on cancer incidence.

5.   The degree of need for access

a.   1) Public interest

i.   The Firefighter Cancer Registry Act of 2018 allows for the collection of data from U.S. firefighters "for the purpose of monitoring cancer incidence and risk factors" (https://www.federalregister.gov/d/2024-06095).

b.   2) What is the information and who gets it

i.   The information is personal and medical in nature, and collected in Firefighter Cancer Registry, with data shared between the CDC and NIOSH. The public cannot see individual data, only published reports. Ideally, epidemiologists who are analyzing the data are the only ones to potentially see any PPI.

Steps 4 & 5 demonstrate the adequacy of safeguards and degree of need for access (and who will have access). Steps 4 & 5 outweigh 1,2,& 3, making this registry constitutional. Per the requested feedback, the outlined time burden is reasonable and the ability to submit everything electronically makes this more accessible for firefighters. Most importantly, the proposed collection of information is constitutional and necessary for understanding cancer risks in U.S. firefighters and developing preventative measures to protect them from workplace hazards.

Comment ID

CDC-2024-0020-0002

Tracking Number

lue-dj0l-vg0t

Comment Details	Submitter Info

Received Date

Mar 30, 2024

Page Count

1

Give Feedback

Privacy & Security Notice (/privacy-notice) | User Notice (/user-notice) |
Accessibility Statement (/accessibility) | Developers (https://open.gsa.gov/api/regulationsgov/) |
FOIA (https://www.gsa.gov/reference/freedom-of-information-act-foia)

Support (/support)

Give Feedback