

# The National Firefighter Registry

## Progress Update

**Kenneth Fent, PhD, CIH**  
Team Lead, Industrial Hygienist

**Miriam Siegel, DrPH, MPH**  
Lead Epidemiologist

NIOSH Board of Scientific Counselors  
October 5, 2021



**NATIONAL  
FIREFIGHTER  
REGISTRY**  
Understanding &  
Reducing Cancer

# National Firefighter Registry (NFR)

One Hundred Fifteenth Congress  
of the  
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Wednesday,  
the third day of January, two thousand and eighteen*

## An Act

To require the Secretary of Health and Human Services to develop a voluntary registry to collect data on cancer incidence among firefighters.

*Be it enacted by the Senate and House of Representatives of  
the United States of America in Congress assembled,*

### SECTION 1. SHORT TITLE.

This Act may be cited as the Firefighter Cancer Registry Act of 2018.

### SEC. 2. VOLUNTARY REGISTRY FOR FIREFIGHTER CANCER INCIDENCE.

**Firefighter Cancer Registry Act of 2018:**  
**CDC/NIOSH “to develop and maintain... a  
voluntary registry of firefighters to collect  
relevant health and occupational information...  
for purposes of determining cancer incidence.”**

# National Firefighter Registry (NFR)

**Mission:** To generate detailed knowledge about cancer in the fire service through a voluntary registry that reflects our nation's diverse firefighters.

**Vision:** To equip the fire service and public health communities with the knowledge they need to reduce cancer in firefighters.



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## Protocol objectives

1. **Collect self-reported information** on workplace & personal characteristics through online portal
2. **Obtain records from fire departments or agencies** to track trends and patterns of exposure
3. **Link with health information databases** including population-based cancer registries and the National Death Index to monitor cancers and deaths

# Who will be included?

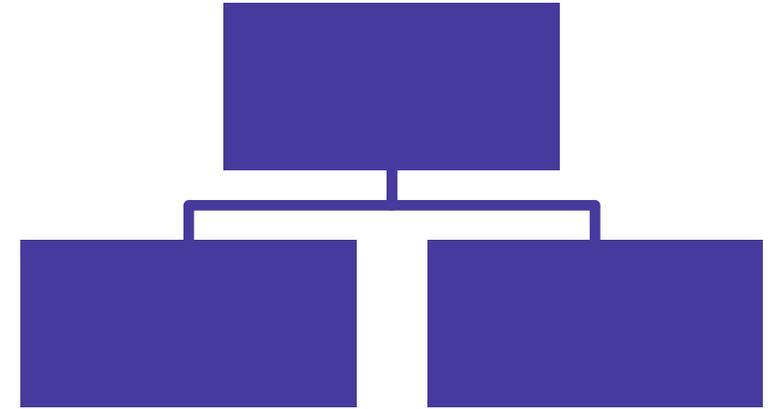
- The NFR will be open to ALL firefighters, not just those with cancer
- Voluntary participation
- Emphasis on women, minorities, and volunteers
- Also interested in sub-specialties like:
  - Instructors
  - Wildland firefighters
  - Fire investigators
- Goal is to enroll 200,000+



# NFR Enrollment Design

## Enrollment routes:

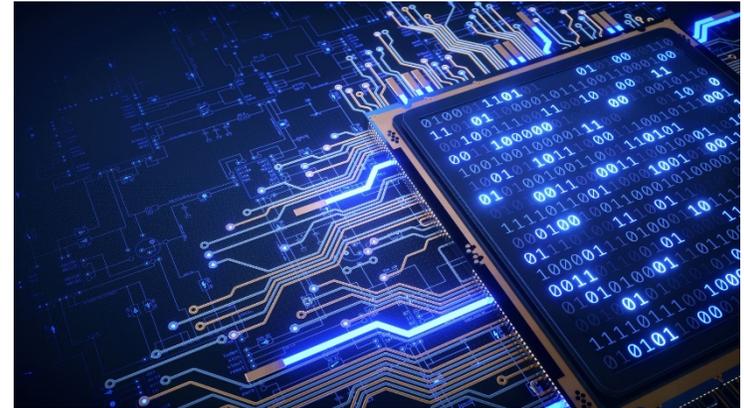
- **Open Cohort (non-probability sample)**
  - Any current/former/retired firefighter
  - Beneficial for diverse sample; but may not be generalizable
- **Targeted Cohort (prospective cohort)**
  - Sampling design to recruit *active* FFs from selected fire depts/state agencies
    - Focused enrollment of women, minorities, volunteers
  - Access fire department records



# NFR Enrollment System (Web Portal)

## *Under development*

- This is taking the longest time because data security is top priority and there are several new Federal security requirements
- Critical that we get this right the first time
- Enrollment will involve:
  1. Informed consent
  2. User profile/information
  3. Enrollment Questionnaire
    - Demographics, work/exposure history, workplace practices, lifestyle, health history



**Enrollment is expected to take 30-45 minutes**

**\* In the future, there will be opportunities to take follow-up surveys**

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### Supplemental exposure data:

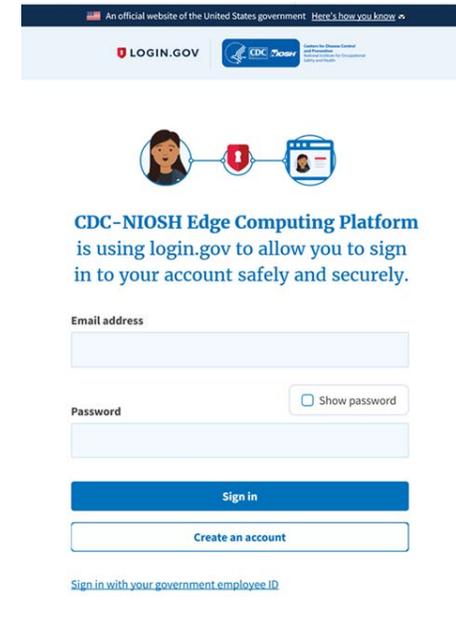
- Fire dept records
- Exposure tracking apps

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# NFR Web Portal Login Process Options

1. Full Registration – No Limits on Data Retrieval/Update
  - Robust participant profile includes employment and health history
  - Participant can view and update previously submitted survey data
  - Requires account creation, multifactored authentication, and **identity proofing**
2. Light Registration – No Retrievable Sensitive Health Information
  - Profile only includes less-sensitive identifiers (name, address, phone, etc.)
  - No ability of participant to retrieve survey responses (sensitive health information)
  - Requires account creation and multifactored authentication
3. No Registration or Profile
  - Functions like a web-based survey
  - No persistent data – each survey is a stand-alone transaction
  - No participant account



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# NFR Subcommittee Meeting (Aug. 13, 2021)

- **General public: 3 oral comments and 7 written comments – many regarding the importance of keeping the process simple**
- **NFRS expressed serious concerns about identity proofing hurting participation rates and producing selection bias**
- **Suggested that Option 2 (Light Registration) was a good balance of collecting the information that is needed for the scientific analysis and making some data retrievable for participants without creating substantial obstacles for participation**
- **Full transcripts and meeting notes available at <https://www.cdc.gov/niosh/bsc/nfrs/default.html>**

# Health Outcome Linkages

Link participants to state/federal records using individual identifiers periodically over time

- **Population-based cancer registries**

- All states & territories (firefighters protect all parts of the country!)
- NAACCR's Virtual Pooled Registry (VPR-CLS)
- Used to determine cancer incidence

- **National Death Index**

- National database of deaths and causes of deaths
- Used to determine cancer mortality



# Health Outcome Linkages

Link participants to state/federal records using individual identifiers periodically over time

*Social Security Number*

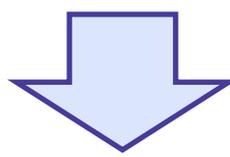
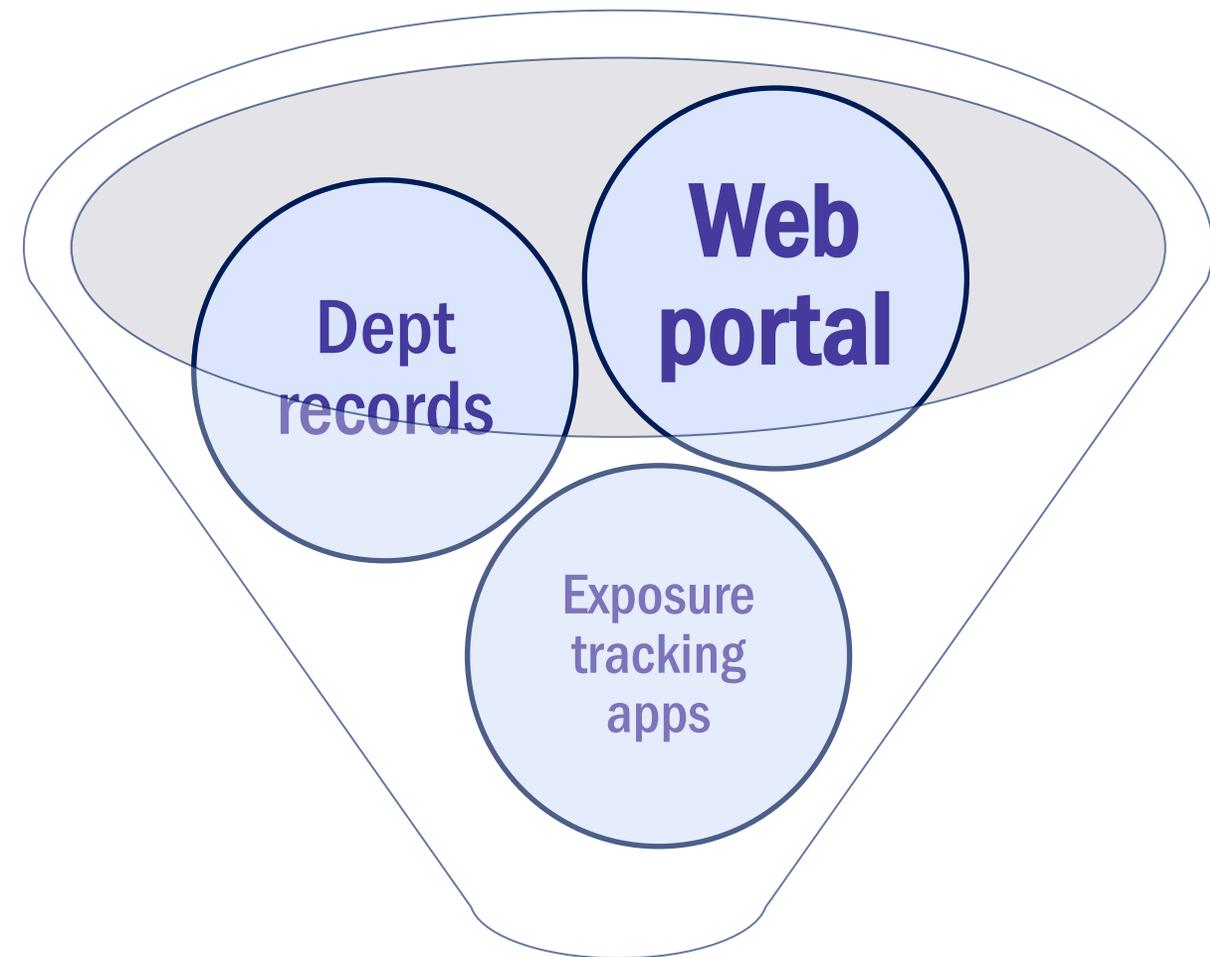
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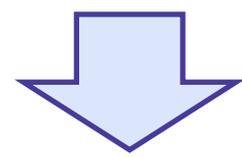
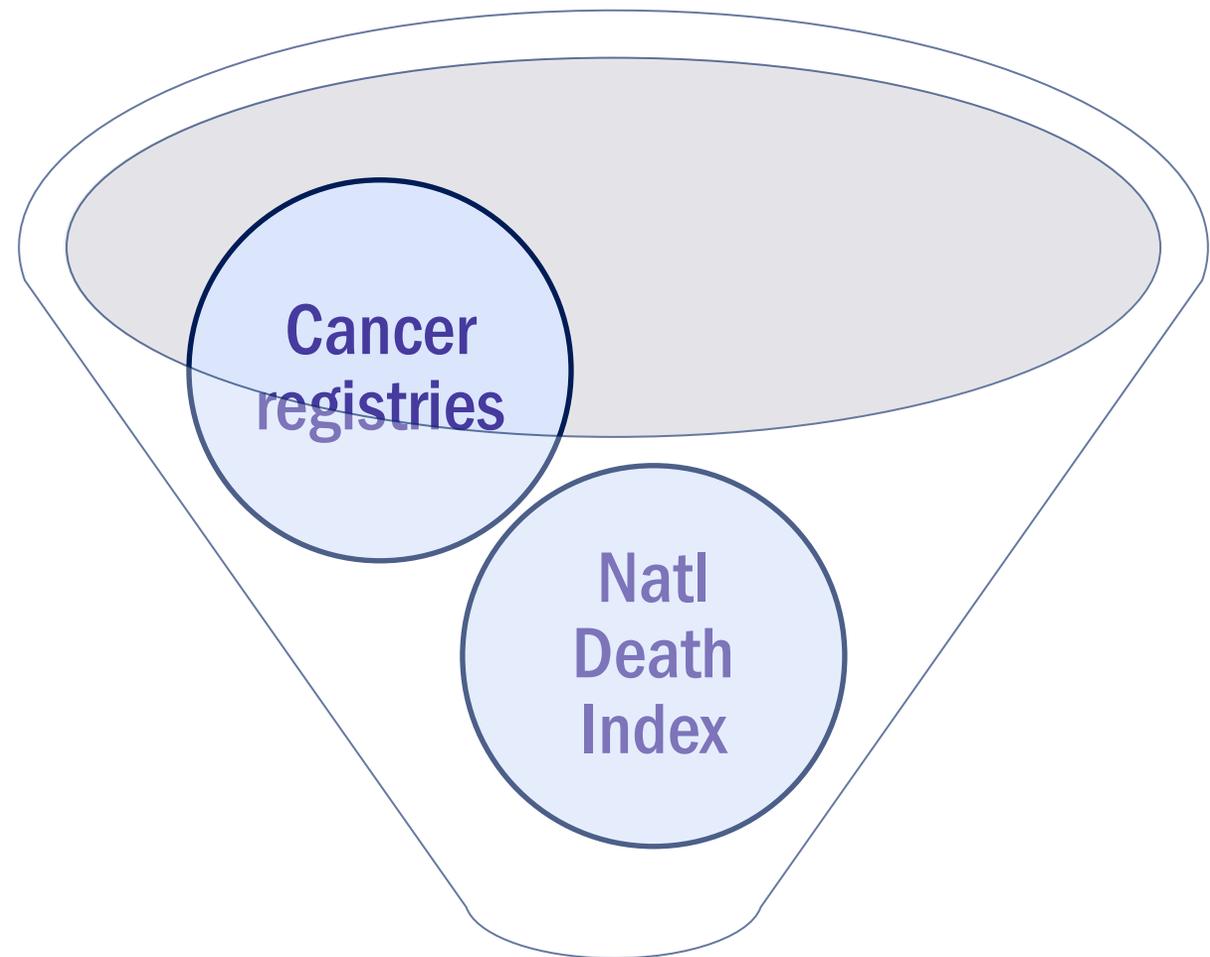
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**NFR [Exposure] Data**

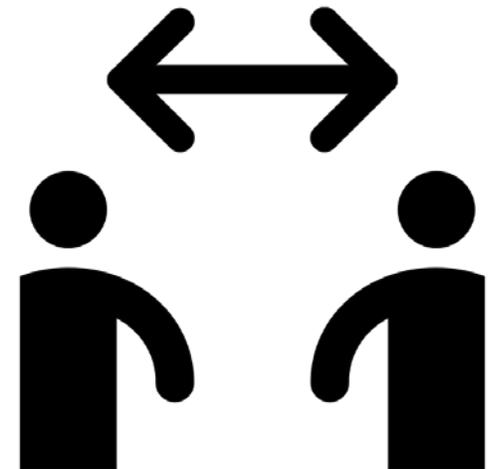


**Health Outcome Linkages**

# Data Sharing & Collaboration

Firefighter Cancer Registry Act stipulates...

- **Protect firefighters' privacy**
  - Obtain an **Assurance of Confidentiality (AoC)**
    - Highest level of protection
- **Make data publicly available**
  - De-identified
  - Secure mechanism for sharing (i.e., Research Data Center)

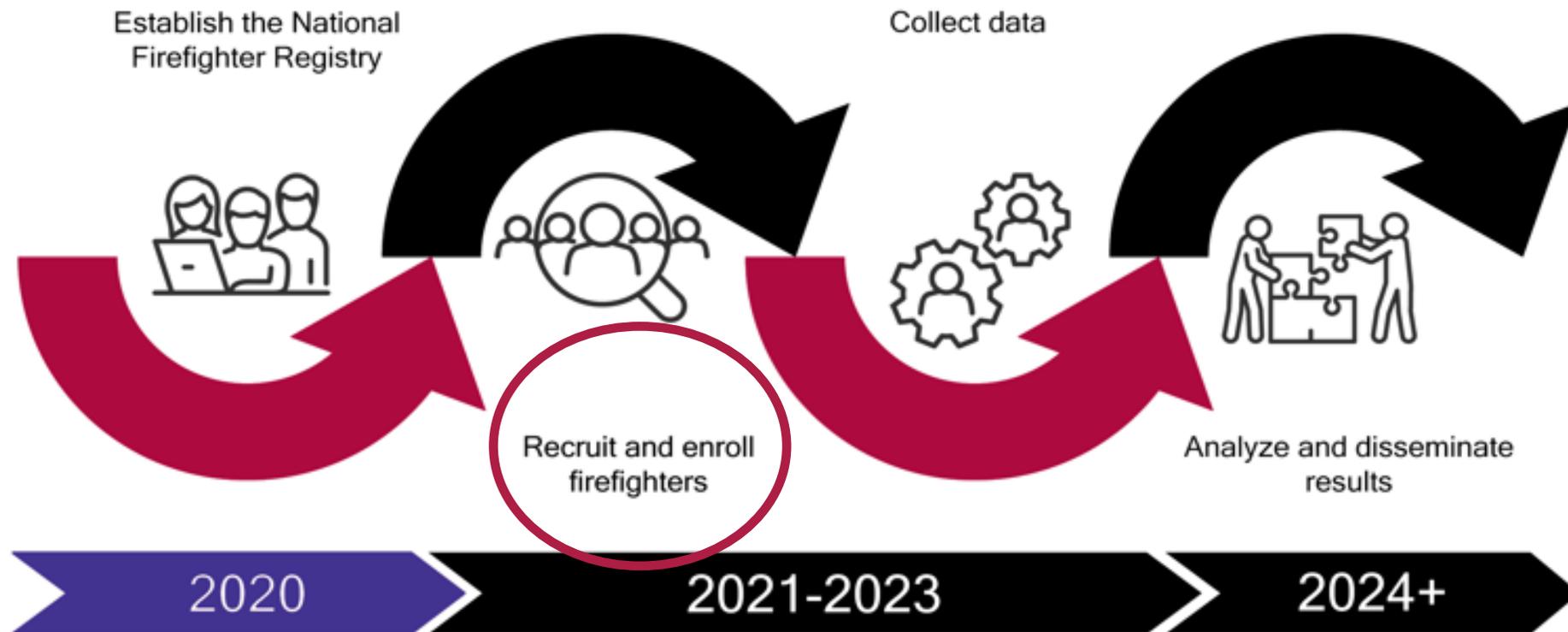


# Potential Limitations

- **Generalizability may be impacted by:**
  - Participation bias
  - Small sample sizes (e.g., among specific subgroups of firefighters)
- **Analyses may be affected by:**
  - Record availability
  - Self-report of past exposures
  - Healthy worker bias
  - Long latency of cancer

# Progress & Timeline

- NFRS reviewed the protocol, consent form, and enrollment questionnaire – posted to the web
- Submitted questionnaire for Office of Management & Budget (OMB) review
- Drafted an Assurance of Confidentiality (AoC) and submitted for CDC review
- Applying for SSN collection and storage
- Began planning/development of enrollment system and database



# NFR Web Portal Project Planning & Timing



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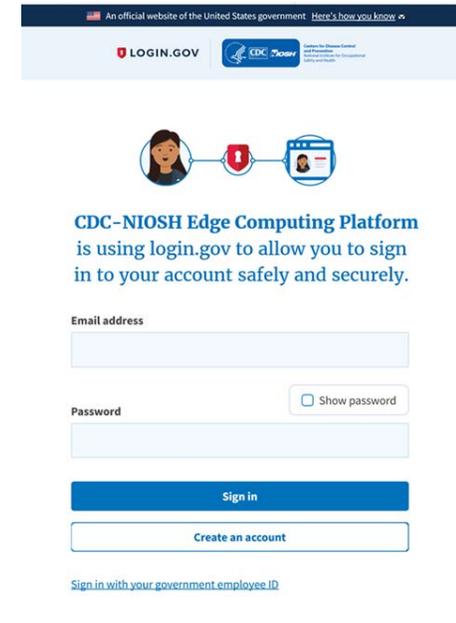
## NFR PLANNING SERVICES

- Business Needs Analysis 6/2021
- Requirements Engineering 9/2021
- Solution Engineering 2/2022
- Implementation 7/2022

Estimated timeline

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# Pros and Cons

## Option 1

- **Pros**

- Allows participants to retrieve previously submitted user profile data for convenience in providing information longitudinally
- Captures employment information and cancer status in user profile

- **Cons**

- Requires identity proofing, which could be burdensome and intrusive
- Identity proofing would require a cell phone or second device to take and upload photographs
- Could dramatically affect participation and result in selection bias

## Option 2

- **Pros**

- Does not require identity proofing
- Easier, less time consuming for participants
- Full enrollment process can be completed on any single device (no scanner or phone necessary)

- **Cons**

- Participant retrieval of data from user profile is limited to less sensitive data only
- Unclear what items are considered sensitive in nature- for example, current department
- Potentially would fail to capture all changes in department or employment status over time
- Potential for discrepancies between previously-entered information and follow-up information that would need to be reconciled

## Contact

[www.cdc.gov/NFR](http://www.cdc.gov/NFR)

<https://www.cdc.gov/niosh/bsc/nfrs>

[NFRRegistry@cdc.gov](mailto:NFRRegistry@cdc.gov)

[kfent@cdc.gov](mailto:kfent@cdc.gov) | [msiegel@cdc.gov](mailto:msiegel@cdc.gov)

For more information, contact CDC  
1-800-CDC-INFO (232-4636)  
TTY: 1-888-232-6348 [www.cdc.gov](http://www.cdc.gov)

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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