# How to
# Register & Provide study-level metadata
# for a study on HEAL Platform

## A multi-part series:

**NIH HEAL INITIATIVE**

### Part 3.0
### How-to Register your study on
### the HEAL Platform (Pre-launch)

**NIH** National Institutes of Health
*HEAL Initiative*

# (Pre-launch)
# How to register your study on the HEAL Platform

**(the study registration process will go live in the coming weeks**

**-**

**links and instructions to access the study registration process will be provided at that time)**

NIH
**HEAL**
**INITIATIVE**

HEAL Platform **Study** Registration Page



Link to the HEAL Platform Study Registration Page will be shared when the study registration process goes live in several weeks

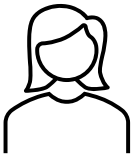# HEAL Platform **Study** Registration Page
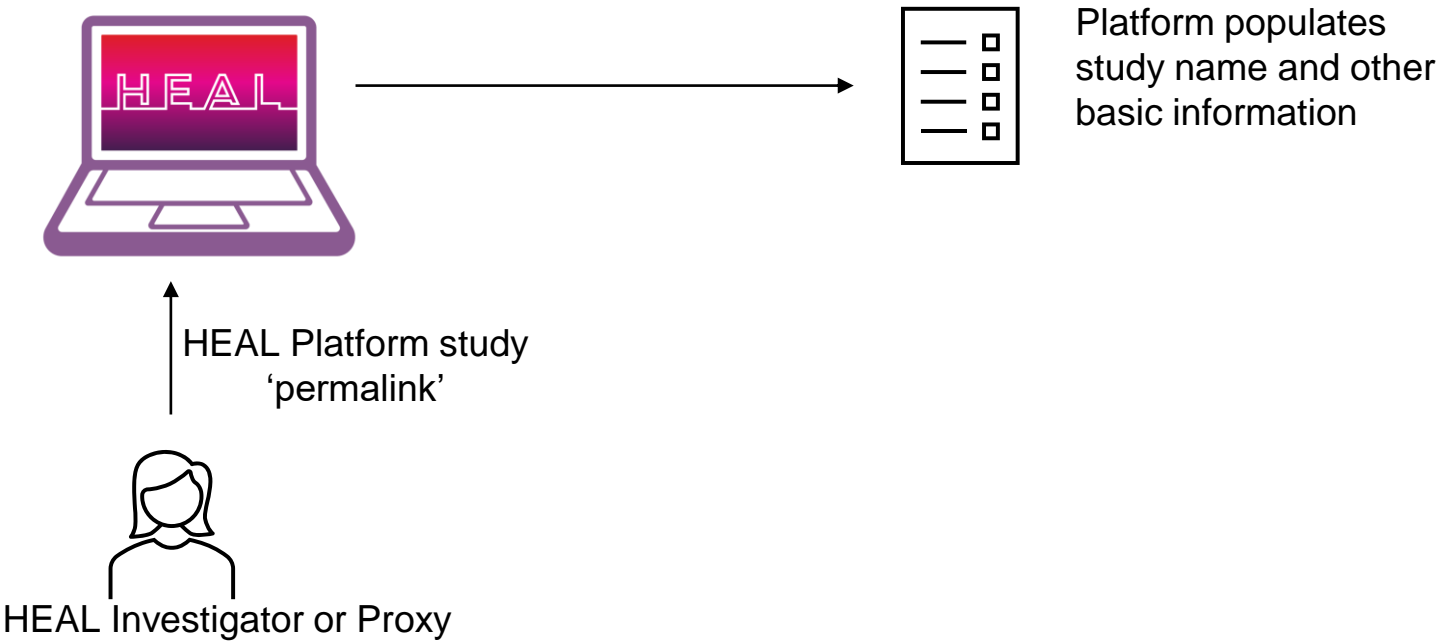
HEAL Investigator or Proxy

HEAL Platform **Study** Registration Page

HEAL Platform study 'permalink'

HEAL Investigator or Proxy

Platform populates basic study information for investigator to view

Platform populates study name and other basic information

HEAL Platform study 'permalink'

HEAL Investigator or Proxy

Platform populates study name and other basic information
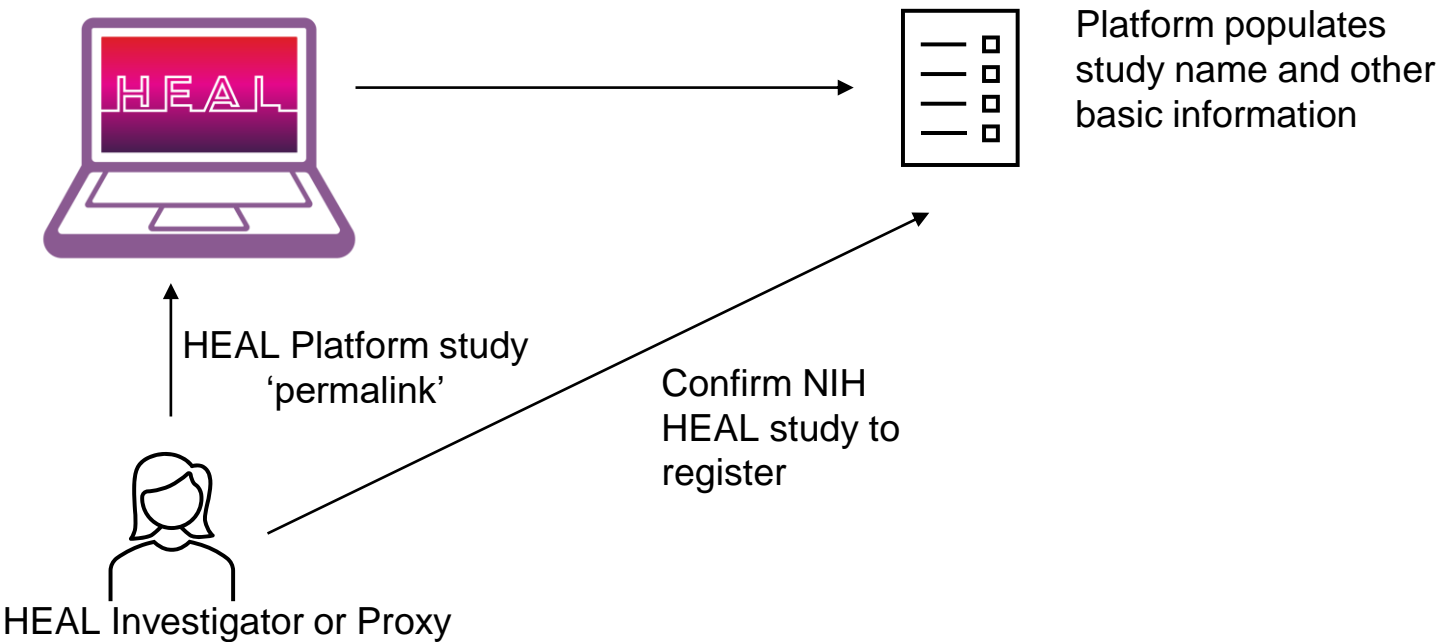
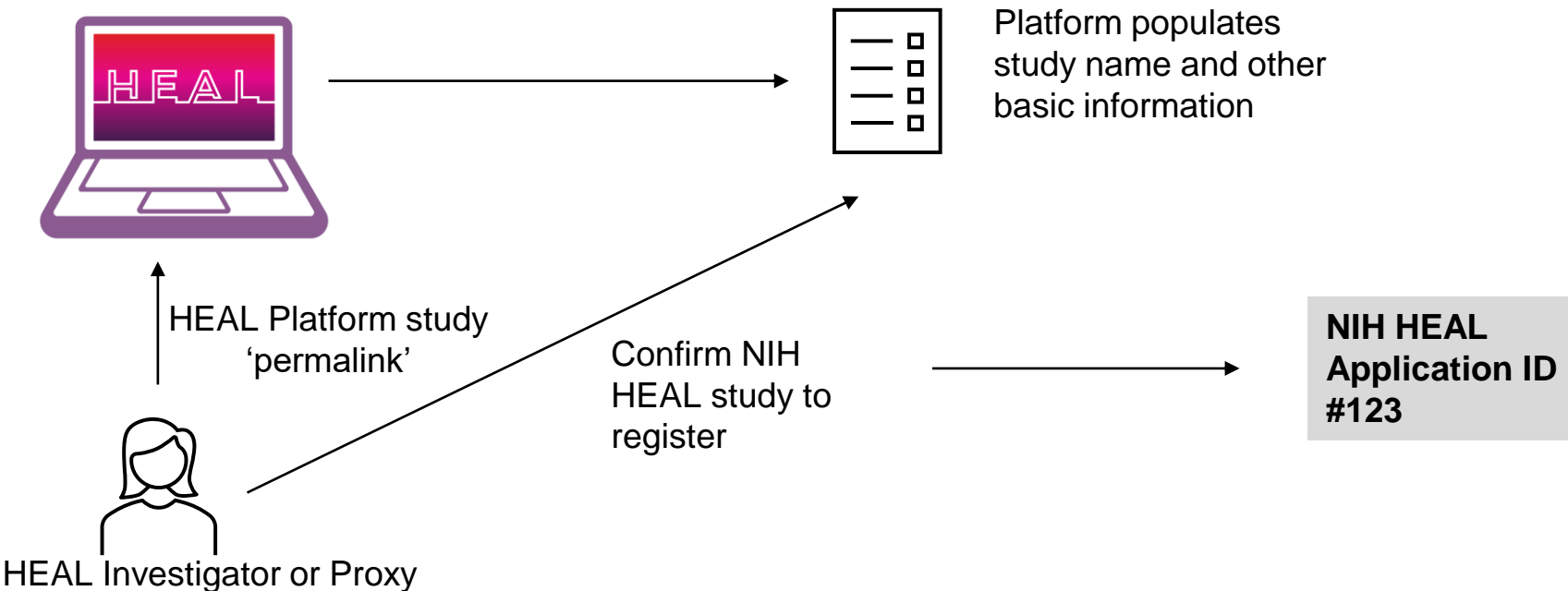HEAL Platform study 'permalink'
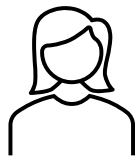
Confirm NIH HEAL study to register

HEAL Investigator or Proxy

This allows the investigator or proxy to 'claim' the NIH application ID# for that study & the associated metadata harvested from NIH RePORTER

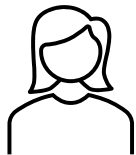Platform populates study name and other basic information

HEAL Platform study 'permalink'

Confirm NIH HEAL study to register

**NIH HEAL Application ID #123**

HEAL Investigator or Proxy

HEAL Investigator or Proxy

NIH HEAL Application ID #123

**NIH HEAL Application ID #123**

HEAL Investigator or Proxy

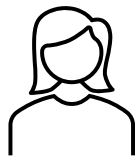**Investigator provides link to ClinicalTrials.gov metadata if applicable:**

**NIH HEAL Application ID #123**

HEAL Investigator or Proxy

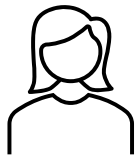**Investigator provides link to ClinicalTrials.gov metadata if applicable:**

1. Is this study a reportable clinical trial? **Yes**
2. Is this study already registered at ClinicalTrials.gov? **Yes**
3. Please provide the ClinicalTrials.gov Identifier (e.g. NCT03407638):**NCT12345678**

HEAL Investigator or Proxy

**NIH HEAL Application ID #123**
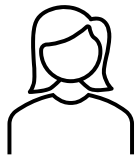
**ClinicalTrials.gov Identifier NCT12345678**

**HEAL Investigator or Proxy**

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 |

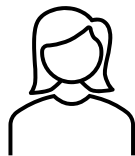**Investigator provides link to home data repository if applicable:**

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 |

**HEAL Investigator or Proxy**

**Investigator provides link to home data repository if applicable:**

1. Is this study collecting or curating shareable data or other work products? **Yes**
2. Is this study already registered at a home data repository? **Yes**
3. Please provide the name of the home data repository: **ICPSR**
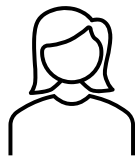4. Please provide the study ID at the home data repository: **12345**

HEAL Investigator or Proxy

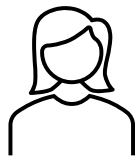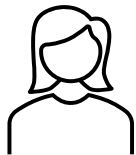| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 |

**HEAL Investigator or Proxy**

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 |

**Platform ingests metadata from all linked sources.**

**NIH HEAL Application ID #123**

**ClinicalTrials.gov Identifier NCT12345678**

**Repository: ICPSR Repository Study ID: 12345**

HEAL Investigator or Proxy

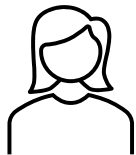**Platform shares harmonized metadata from all available sources to a CEDAR template instance:**

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 |

HEAL Investigator or Proxy

**Platform shares harmonized metadata from all available sources to a CEDAR template instance:**

- A CEDAR template instance is an easy-to-use, interactive web form.
- It will contain fields for all metadata in the HEAL Study-level core metadata fields/model.
- The Platform will harvest metadata from all metadata sources the investigator indicates on the study registration page, and 'answer' as many of the 'questions' in the CEDAR template instance (form) as possible with that information.
- The Platform will then share this partially filled-out CEDAR template instance (form) with the investigator.
- The investigator will be asked to 'answer' the remaining unanswered 'questions' in the CEDAR template instance (form), and the Platform will automatically harvest those answers.
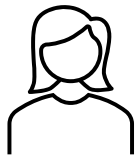
NIH HEAL INITIATIVE

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 |

**HEAL Investigator or Proxy**

**Platform shares harmonized metadata from all available sources to a CEDAR template instance:**

1. Do you have a CEDAR user account? **Yes**
2. Please provide your CEDAR UUID: **12a-3c-4d5**

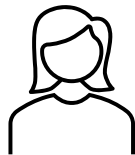| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 |
|---|---|---|

HEAL Investigator or Proxy

**Platform shares harmonized metadata from all available sources to a CEDAR template instance:**

1. Do you have a CEDAR user account? **Yes**
2. Please provide your CEDAR UUID: **12a-3c-4d5**

- In order to provide supplemental metadata via the CEDAR template instance (form), investigators or proxy will need to obtain a user account on CEDAR
- Investigators or proxy may create an account and username ahead of time by navigating to https://cedar.metadatacenter.org
- See the guide on 'How to find your CEDAR user account UUID' for step-by-step instructions on how to find your UUID once you have a CEDAR user account
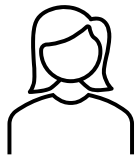
HEAL Investigator or Proxy

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 | CEDAR UUID: 12a-3c-4d5 |
|---|---|---|---|

**HEAL Investigator or Proxy**

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 | CEDAR UUID: 12a-3c-4d5 |

**Platform shares audit of metadata provided via existing sources**

| Metadata Provided by Existing Sources |
| --- |
| Study Title, Study Description, Investigator Name, Investigator Affiliation, … |

HEAL Investigator or Proxy

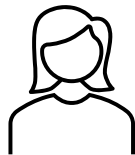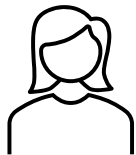| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 | CEDAR UUID: 12a-3c-4d5 |

**Platform shares audit of metadata provided via existing sources AND supplemental metadata needed:**

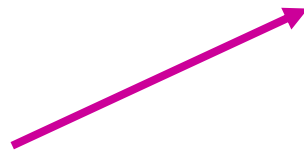| Metadata Provided by Existing Sources | Supplemental Metadata Needed |
|---|---|
| Study Title, Study Description, Investigator Name, Investigator Affiliation, … | Treatment Level, Treatment Mode, Treatment Type, … |

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 | CEDAR UUID: 12a-3c-4d5 |

HEAL Investigator or Proxy

**Platform shares access to Platform-created CEDAR template instance & provides a link to CEDAR to provide supplemental metadata in the form:**
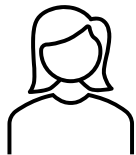
| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 | CEDAR UUID: 12a-3c-4d5 |
| --- | --- | --- | --- |

HEAL Investigator or Proxy

**Platform shares access to Platform-created CEDAR template instance & provides a link to CEDAR to provide supplemental metadata in the form:**

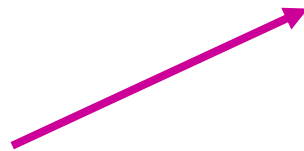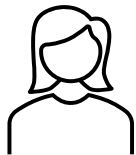**Link to CEDAR**

**Instructions:** Log in to CEDAR with CEDAR Username linked to the UUID provided on HEAL Platform Study Registration page.

Navigate to "Shared with Me" to find your Platform-created CEDAR template instance. *Provide supplemental metadata in the form*

**NIH HEAL INITIATIVE**

| NIH HEAL Application ID #123 | ClinicalTrials.gov Identifier NCT12345678 | Repository: ICPSR Repository Study ID: 12345 | CEDAR UUID: 12a-3c-4d5 |
|---|---|---|---|

HEAL Investigator or Proxy

**Platform shares link to CEDAR to provide supplemental metadata in Platform-created CEDAR template instance :**

Platform will automatically harvest supplemental metadata provided by investigator or proxy in the CEDAR template instance (an easy-to-use, interactive web form)

**Link to CEDAR**

**Instructions:** Log in to CEDAR with CEDAR Username linked to the UUID provided on HEAL Platform Study Registration page.

Navigate to "Shared with Me" to find your Platform-created CEDAR template instance. *Provide supplemental metadata in the form*
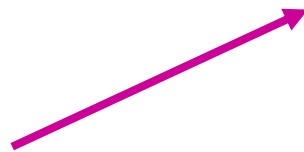
# Some final notes

➡ See the guide on **'How to find your HEAL Platform-created CEDAR template instance'** for step-by-step instructions on how to find your HEAL Platform-created CEDAR template instance once you have registered your study on the HEAL Platform and are ready to view metadata harvested by the Platform, and to add supplemental metadata via the interactive form interface

➡ See the guide on **'How to provide supplemental metadata in your HEAL Platform-created CEDAR template instance'** for step-by-step instructions on how to use your HEAL Platform-created CEDAR template instance to provide supplemental metadata via the interactive form interface

➡ HEAL Platform may provide access to a file containing all HEAL study-level core metadata to investigators or proxy for download and submission to home data repository

➡ HEAL Platform study registration process may also allow investigators to specify if the study they would like to register is a distinct study among other within a single HEAL award