

Transcript

CATHERINE: Hello everyone. We're going to go ahead and get started today. Thanks for joining us. Welcome to Standardize Your Research Data with the NIH Common Data Element Repository. I'm just going to adjust my screens and then we will dig in. Okay. So the purpose of today's training is to familiarize you with Common Data Elements, or CDEs, and the NIH Common Data Element Repository or the CDE-R. I'm Catherine Staley from the National Library of Medicine's Office of Engagement and Training. Here with me today are my Office of Engagement and Training colleagues Kate Majewski, Mike Davidson and Michael Tahmasian. And we're joined by Robin Taylor from the NLM's Division of Library Operations who will be helping me answer your questions. Robin has been with the NLM for almost five years as a Technical Information Specialist and is the Product lead for the CDE-R.

During today's training, you'll have the opportunity to ask questions and practice searching in the repository, so let's review how we'll interact in Zoom. Captions are available for this class. Click the Show Captions button at the bottom of Zoom to see those. We do have everyone muted to cut down on background noise. If you have a question or a comment, please use the chat box and send it to everyone. I won't be able to answer messages sent directly to me, but Kate will be monitoring your questions throughout and I'll pause frequently to see if there's anything that I or Robin need to address.

To keep us on track, we're providing a handout that you can download and follow along with, and Kate is putting a link to the handout in the chat now. Thank you, Kate. If you're working on a small screen and it's not feasible for you to work on a handout during the presentation, feel free to just listen along and we'll share a link to the answer key at the end of class, which you can use to review. During class I will also be occasionally asking for your nonverbal feedback using the Reactions feature. The Reactions feature is accessible from the Reactions button at the bottom of your screen, so please find that button now and give me a thumbs up to indicate that you found it. Some devices may not allow for this type of interaction, and if you can't find the Reactions button on your device, feel free to use chat to respond when I ask you to. And I see lots of thumbs, so thank you very much for that. Okay.

Today, we'll explore a variety of ways that CDEs and the Repository can support you and your work. But to get us started, I want to put them in the context of the NIH's mission. Both the NLM and NIH have identified common data elements as a tool for facilitating the interoperability of data. Ensuring that biomedical research data is interoperable is a step towards making that data FAIR. The FAIR Principles recommend that data be findable, accessible, interoperable and reusable. The repository is one way that the NIH supports researchers in aligning with the FAIR principles. Additionally, in the NLM strategic Plan for 2017 to 2027, CDEs support the objective to connect the resources of a digital research enterprise. And in the NIH Strategic Plan for Data Science, the use of CDEs is encouraged to improve accuracy, consistency and interoperability among data sets within various health and disease

research. And finally, you're probably aware of the new NIH Data Management and Sharing Policy that went into effect in January 2023. Common data elements can be part of a compliant plan. If you'd like to learn more about that plan, there is a link on the handout to it. If you know how to locate CDEs in the CDE-R, you'll be better equipped to support these goals.

Therefore, today's training is going to specifically focus on how to navigate the repository and find CDEs that will assist you with your data collection process. And this is our agenda for the session. So first we'll review what you need to know before using the repository, like what a CDE is and special repository features that will aid in your searching. Then I'll demonstrate the CDE-R live for you and you'll have the opportunity to practice on your own. And finally, we'll review how to save CDEs for later and how to get help if you're stuck.

Next, I would like to get a sense of who you are and your work. So if you could please take a moment to tell us in the chat your title or your role and the name of your organization. Okay, I see Research Data Librarian. We do have some librarians, professors, Senior Lead for Clinical Informatics, wonderful, recent MLIS grad, fantastic. Thank you all for your responses. It's great to see where folks are coming from as well.

Next, I would like to gauge your familiarity with CDEs. So we'll use a poll for this question and I'll ask Michael to launch that poll now. Thank you, Michael. So please select the answer that best represents your level of familiarity with CDEs. And I see lots of folks already responding. Thank you. I'll give you a minute to do that. Fantastic. It looks like most of us have responded. So I'm going to end the poll and share these results so we can look at them together. So it looks like many of us are maybe not at all familiar, which is totally fine. We're going to talk a lot about CDE's today and what they are. And then kind of in the middle, we've got some moderately and slightly familiar, and some of you are very familiar. So it's great to see sort of the spread of knowledge, and I hope that everyone leaves here having learned something new about CDEs and the Repository. Okay close that poll.

So we can actually use the data that you just provided to explore some reasons you might consider using CDEs in your projects. Let's say I'm writing a report after this training to summarize how it went, and I want to include some data about the participants. I could start by entering each of your answers in a spreadsheet, and then I might have to standardize how your organization's name is represented on the side. I've used the acronym like NLM to standardize the results, but I could also write out the name as in National Library of Medicine, or both, with the acronym and parentheses beside the name. This is just a small set of data, so it wouldn't take me too long to standardize. But what if I wanted to compare responses from all of our NLM trainings, not just this one? With more data, it could take longer to standardize, and I'd have to ask other trainers to standardize their data too, so that we could combine our results. Plus, what if another trainer asked about their audience's familiarity with CDE's, but they asked the question in a different way? For example, maybe they asked the audience to describe their level of familiarity in their own words. It would be really hard to compare those free text responses to the responses that you just provided. We would have two very different sets of data, like the

ones on this slide. If my colleagues and I came together and created a survey that asked all of our participants to answer questions using the same format, we'd be able to combine and compare our data quickly and efficiently. We'd have results sooner and could adapt our trainings a lot faster based on who participates. And you probably want to compare your research results to those of your colleagues who study similar topics, and CDEs can help you do that.

So as we just saw, some of us are very familiar with Common Data Elements, and for many of us it's a brand new topic. So I want to review a definition of CDE so that we're all on the same page, and this definition is the answer to #1 on your handout. Common Data Elements, or CDEs, are standardized, precisely defined questions paired with a set of specific allowable responses used systematically across different sites, studies, or clinical trials to ensure consistent data collection. In other words, it's a standardized way of collecting a particular piece of information from a respondent. No matter who is asking the question, it's asked in the same way and respondents have the exact same answers to choose from. This applies to when respondents are filling out their own answers or if the researcher is recording the answers on their behalf.

Here's an example of a CDE from the Repository. It's titled Usual Place of Health Care Type and it asks, "Is there a place that you usually go to when you are sick or need advice about your health? Select all that apply." That is the standardized, precisely defined question. Respondents or the researcher can answer with one of these specific allowable responses: A doctor's office or community Health Center; Walk-in clinic, urgent care center, or retail clinic in a pharmacy or grocery store; Emergency room; A VA Medical Center or VA outpatient clinic; Some other place; There is no place; Don't know; Refused/Not reported; or, Unknown.

Here's another example of a CDE. This one is titled Date of Chest Examination. It asks, "What was the date of the imaging examination?" The specific allowable response for this one is the date, and you'll see other CDEs in the repository that allow responses like the time, a number, or a date.

After viewing those two examples, you might be thinking about how CDEs can fit into your workflow. First, CDEs can save resources, including your time and your labor. Rather than writing your own instrument or data collection tool, you can find one in the repository. Using CDEs also advances science because it allows researchers to compare data and results across studies. Imagine if you could seamlessly compare your results with researchers across other institutions without having to coordinate your efforts, because you're both already using CDEs. And finally, you might be required to use CDEs to comply with organizational policies. Or you may assist researchers at your institution with writing a data management and sharing plan for a grant. Many grants awarded by the NIH now strongly require, now require, or strongly encourage the use of CDEs, so the Repository can help you meet that requirement. So give me a thumbs up if you're required by organizational policy or a grant to use CDEs, or if you're helping others find CDEs to comply. Wonderful. I see a couple thumbs. Great. Thank you for those responses.

Let's take the case of the NHLBI initiative called the Collaborating Network of Networks for Evaluating COVID-19 and Therapeutic Strategies, or CONNECTS, which illustrates how CDEs can be used. For all of these reasons, the goal of CONNECTS is to mobilize and coordinate the US clinical trial infrastructure to find the most effective therapies for treating COVID-19. It consists of over 40 networks and cohorts with over 1000 participant sites across six different studies. To coordinate and connect these studies, the NHLBI created a set of Common Data Elements that trials funded through this program will implement. With these CDEs already available, this gets the research off the ground faster. A recent CONNECTS study called the Novel Experimental COVID Therapies Affecting Host Response, or NECTAR, has multiple sites across the country, as illustrated by this map. And because they're using CDEs, researchers at these sites can combine their data easily, regardless of where it was collected from.

The focus of our training today, the Common Data Element Repository was developed to help you find CDEs. It's a free, collaborative platform designed to provide researchers with CDEs that have been recommended or required by NIH institutes and centers or other organizations for use in research and for other purposes. The NIH CDE Governance Committee reviews and assesses CDEs submitted by ICs, and they work closely with the NIH CDE Repository Team at the NLM. Currently the repository has over 23,000 CDEs from across 18 organizations. In the next part of this training, I'm going to highlight two key features of the Repository that can assist with your search. Those are NIH-endorsed CDEs and Forms & Bundles and this will prepare you to actually search the Repository in a few minutes.

The Repository includes NIH-endorsed and non-NIH-endorsed CDEs, and that's the answer to #2 on your handout. NIH-endorsed is the designation in the repository that means CDEs were reviewed and approved by an expert panel and meet established criteria. This feature is intended to help you identify CDEs that are ready to use. NIH recognized bodies like institutes or research initiatives may submit CDEs to the NIH CDE Governance Committee for consideration for endorsement. When the Governance Committee deems the CDEs as endorsed, the NLM will publish the CDEs in the repository and designate them as NIH-endorsed. On the slide is the criteria for endorsed CDEs. These criteria were developed by the NIH Scientific Data Council. To be endorsed, a CDE must adhere to this list. Clear definition of variable and measure with prompt and response. Documented evidence of reliability and validity. Human and machine-readable format preferred. Recommended or designated by a recognized NIH body. And Licensing and IP status clear. The expectation is that the designation of CDEs as being endorsed by the NIH and making those CDEs discoverable and accessible through the Repository will advance the use of CDEs and NIH supported and conducted research. For you, this means that you can more quickly identify the CDEs that have met the set of criteria and are ready to use.

Currently, there are two collections of NIH-endorsed CDEs and the NLM anticipates adding two more collections this fall. One set is from the Project 5 collection, which were developed for a wide spectrum of COVID-19 research, including translational, clinical and applied research. And the other set is the NHLBI CONNECTS Organ Support CDEs. If a CDE is endorsed, you'll see this

gold ribbon icon in the repository. You can search directly in the NIH-endorsed CDE collection or limit your search results to Endorsed CDEs, which we'll see how to do in a few minutes.

The second feature I want to highlight is forms, and this is the answer to #3 on your handout. Forms are a group of questions or variables, aka CDEs, with specified sets of allowable responses that are used as a set for particular research or clinical reasons. Forms can collect a lot of data about a participant all at once, like a family history. Or they might assess or measure something like pain or depression or the seriousness of an adverse effect from a medication. Forms will often include a system for scoring a participant's responses, and once they've completed filling out or responding to a form's questions, the administrator will tally up their score. Different scores will lead to different conclusions or interventions.

Some repository forms recreate validated instruments that were created outside of the repository. So, for example, this Audit-C Questionnaire shown here is intended to identify alcohol use disorders and was developed by the World Health Organization in 1998 and it includes 3 CDEs. The key thing to remember about forms is that they are composed of individual CDEs, and those CDEs come together to measure or assess something.

Sometimes you'll see forms in the Repository that are designated as bundles, and this is the answer to #4 on your handout. A bundle is a form that is indivisible, and individual CDEs pulled from them are not considered valid. Bundles are clearly marked in the repository with a blue banner at the top of their record that states, "This form is a bundle. Bundles are indivisible. They are not considered valid and reliable if not used in their entirety as intended." CDEs that are part of a bundle are also clearly designated in the repository with a blue banner that says, "This CDE is part of a bundle. All CDEs within a bundle must be used together. Go to bundle," with a link to its bundle record. This is a new feature in the repository and staff are continuously identifying and designating bundles and we'll see examples of forms and bundles today.

OK, a lot of information, but now we are ready to search the Repository. Before we dive in, I want to review what we've covered so far. So Michael's going to launch another poll for us with a few questions for you to answer that will check your understanding of CDEs so far. Thank you, Michael for launching that. These are also Questions #5 through #7 on your handout if you want to follow along there. So I'll give you a minute or two to answer these questions and then we'll review the answers together.

Okay, it looks like most of us have had a chance to submit our answers. So I'm going to end the poll and share our results and then we'll review the answers together. All right. Looks like we are all getting the main points here. So to review, number one [#5], what can you find in the CDE-R? You can find CDEs, forms and bundles and we'll see examples of all of those today. #2 [#6] Which CDEs were reviewed and approved by the NIH? Those are endorsed, So endorsed CDEs have been reviewed and approved by the NIH. And then finally, it is true that in the CDE-R, a bundle is a form that is indivisible and individual CDEs pulled from them are not considered valid. Great. Thank you so much for participating in that. And I'm going to close the poll now.

And this is actually a good time to pause for questions before we jump into the Repository. So Kate, have we had any questions come in?

KATE: In fact, we have. We have a question from Carol. Carol would like to know **how often are the CDEs in the repository updated?** I think this is a question for Robin.

ROBIN: Hi, thanks, Kate. So to answer your question, Carol, new CDEs are added to the repository on a continuous rolling basis once they've been endorsed by the NIH CDE Governance Committee. But once they're in the Repository, updates are the responsibility of the steward of the CDE. The steward is the group that submitted the CDEs to the Repository. So we rely on the steward to bring changes to our attention. So the CDE Repository Team here at NLM, we are not subject matter experts. So it's really up to the stewards to maintain those CDEs. But we are working with the NIH CDE Governance Committee to develop processes and policies for regular reviews and updates of the CDEs to make sure that everything is being reviewed on a regular basis. Thanks.

KATE: Thanks Robin. One more question just popped in. Brian would like to know **do CDEs get superseded by new ones?**

ROBIN: They can be, yes. We do have versioning in the CDE Repository and so to kind of feed off the previous answer I just gave, if a group notices that one of their CDEs needs to be updated and they have say a new list of answers for it, they would submit the new CDE with the updated answer list and that would become the current version and the older version would be archived. It would still be available if you really wanted to see it, but it would be archived and harder to find. So yes, short answer is yes.

KATE: Thanks Robin. Another question from Deb, **when CDEs from the repository are used, how should they be cited or acknowledged?**

ROBIN: Well, we are exploring different ways for citing CDEs. Every CDE has a unique identifier within the repository that can be used to cite that particular CDE. I know there's sometimes standard ways to cite other systems like an article or DOI or something. We don't have anything like that yet. If we do, we'll publicize that for sure. But for now, you can link to a CDE using the NLM identifier, and I think Catherine shows that later on in the session. If she doesn't, I'll be happy to answer a question about it later.

KATE: Thanks. From Vandana, **do you have a way to track usage of CDEs?**

ROBIN: This relates to the previous question. Because there's no standard way right now to cite the CDEs, there's no way that we have right now to track usage of CDEs. This is definitely an ongoing conversation, because there's a lot of interest in that. I think probably within the different institutes that are recommending that their researchers use CDEs, I'm sure some of them have their own ways of making sure within their programs, and within their branches, that their CDEs are being used by their researchers, but we don't yet have a trans NIH way of

tracking usage or beyond NIH way of tracking usage of CDEs. But it's definitely something that we would like to have someday, so stay tuned.

KATE: Excellent. Thanks. One more question for now, **are CDEs only used in human trials?**

ROBIN: That is a great question. The answer is not entirely. The CDEs in the repository, that you've probably seen if you've taken a look, are mostly clinical CDEs. However, there are some. There's one set of preclinical CDEs in the repository now for traumatic brain injury from NINDS. And I know that there are other groups at NINDS and possibly beyond NINDS across NIH that are working to develop and share more preclinical CDEs. So I hope that answers your question.

KATE: Excellent. Thanks Robin. Okay. We'll stop the questions for now but keep them coming in chat and we'll move on to the next part of the class. Back to you, Catherine.

CATHERINE: Great. Thank you, Kate and Robin. Yeah, wonderful first set of questions. OK, so we are now ready to search the Repository. If you'd like, you can follow along with this demonstration on your own device. And Kate is going to put a link in the chat to the Repository and I will now share that on my screen. So as we go along, I'll try to make the screen bigger when I can. But you can also adjust the size of the demonstration on your own screen by going to View options at the top and adjusting the zoom ratio. So give me a thumbs up when you've got the Repository open and you're ready to go, seeing lots of thumbs. Wonderful. Fantastic.

OK, so anyone can search the CDE-R and see results, but to access all of the Repository's features you'll need a Unified Medical Language System Terminology Service account, or a UTS account. So you should see in the upper right corner of your screen a sign in button to either sign into an existing account or sign up for a new one. I'm already signed in, so you see my profile name there. If you don't have an account, I encourage you to wait until after this training to sign up. You can still follow along on your own device and see almost everything, and as we go, I'll point out any differences between what the Repository looks like when you are or aren't signed in.

Next, I'm going to point out some features of the Repository's home page. The Repository's default search is for NIH-endorse CDEs. You can switch to searching for all CDEs or forms by clicking on the tabs above the search box. You can also select CDEs or forms from the menu across the top of the page to search or browse either type.

So let's start with searching within NIH-endorsed CDEs using some keywords. Imagine that you're designing a research study and you want to collect data about the medications a patient being treated for COVID-19 receives. We can search within the endorsed group with the keyword medications to see if any CDEs are available on that topic. So I'll just type in medications and search and I get a few results. I want to look at the second result here to point out a couple things about the results page for you. So notice the yellow ribbon icon that indicates the CDE is NIH-endorsed. Beside that is the CDE title which is COVID-19 Specific Medication Type. And below the title is a short definition of the CDE. Below the definition is its

registration status, highlighted in green, and the CDE is marked qualified. The registration status indicates how broadly a CDE is being recommended or used and we'll look more at registration statuses later.

Also listed is the Steward, which is the answer to #8 on your handout. Robin mentioned the steward earlier when she was answering a question. Every CDE has a steward which is the organization or project responsible for the CDE in the Repository. This CDE steward is Project 5 COVID-19. So if this CDE ever needs an update or it changes in any way, the steward is responsible for working with the Repository to make those updates. Below the Steward is listed Used by. Typically the Steward is also who the CDE is used by, like our example here, although anyone can use it. And to the right of all this information is a preview of the values list if the CDE has one. So I'll click on the CDE title to see its full record. At the top of the record, we see the notice that the CDE is part of a bundle with a link to its bundle, and we'll return to that in a moment.

If you'll recall our definition of CDE earlier, it should have a precisely defined question in a set of specific allowable responses. This CDE's question text, listed right below its title, is "What medications did the patient take to treat COVID-19?" That's the precisely defined question. The permissible values are the specific allowable responses to that question, and if you scroll down a bit you see those arranged in a table. You should be aware that if you're not logged into a UTS account, then the Permissible Values section could be missing some information. You might see the message "Log in to see values." The first column of the table PV Labels includes the allowable answers to the question. In other words, these are the responses that someone answering the question can choose from. The next column PV Definitions includes how those values are defined or described, and the other columns relate to Concepts and Codes. Concepts describe the meaning of a permissible value. Codes are how the responses would be recorded during data collection for interoperability between studies. Codes might come from a system like LOINC or NCI Thesaurus, or they might be what we call local codes like 123, or Yes/No, or similar. And there's also a feature that allows you to see these codes translated to other systems like LOINC, NCI Thesaurus, SNOMED CT US, or UMLS codes. And that feature will appear above this table when it's available. If you keep scrolling, you'll see a lot more details about the CDE. We'll cover some of these features later today, but I'll refer you to the Repository Help Guide For more information about them.

I'm going to scroll back up to the top of this record to that notice that the CDE is part of a bundle. And to see its bundle I'm going to click on the bundle link and that takes me to the record for the bundle. As we discussed earlier, some forms are designated as bundles, which is the case here. This form is titled Project 5 - Disease Specific Medications and it's a bundle as we see this notice at the top in the blue banner and if I scroll below the title, I see the bundle and the CDEs that are a part of it. And the second one is the CDE that we just viewed COVID-19 Specific Medication Type.

All right, it is your turn to search. So I have an exercise here for us, so please search within the NIH-endorsed collection for a CDE that collects the employment status of the respondent and once you found it, put one of its permissible values in the chat and then we'll review how to find that together.

Okay. I'm seeing multiple folks putting in Working without pay is one of our permissible values. Retired. Employed. Part Time? Excellent. Looking for work. Unemployed. Yes. Employed Full time. Great. Looks like we are finding it. Yeah. Not employed and Not looking for work. Retired. Excellent. This one has a lot of options to choose from. Okay great. Looks like many of us have been able to locate it and have put a permissible value in the chat.

So I will go back to the Repository and demonstrate how to find that. So first I'm going to go back out to the CDE-R home page and I'll search for employment status in the NIH-endorsed CDE search box and this gives me 4 results and based on the definition of the first one, a textual description of a person's employment status. I think that's a good fit, and I think this is the one that most of us found, so I'll click on the title to look at those permissible values, scroll down to the table, and here are the different answers that you put in the chat. Fantastic.

Next we're going to explore searching within all CDEs in the repository, not just the NIH-endorsed ones. The repository has over 23,000 CDEs and 137 of them are NIH-endorsed for now and that number will grow, so you might want to search outside of the endorsed group for certain topics. So I'm going to go back out to the repository homepage and this time I'll click on Search All CDEs above the search box. Let's say I want to find CDEs that measure a person's physical activity so I can search for the keywords physical activity and when I do that I get over 200 results. And because it's so many results I can use some of the filters on the left hand side of the screen to help find CDEs that match what I need. So first I'm going to try limiting to NIH-endorsed CDEs by clicking on the box beside NIH-endorsed and when I do that, notice that now under active CDE filters I see my search terms and I see NIH-endorsed CDEs. So using that filter gave me 4 results. But looking at these, I don't think that any of them are measuring a person's physical activity. So I'm going to click the X beside NIH-endorsed CDEs and remove that filter.

If I can't find an endorsed CDE that matches what I need, there's a few other criteria I can use. So first I'll look at the collections options. These are the organizations or initiatives with CDEs related to your search and if your organization is listed there, then you might see if it has any related CDEs. I'll click on the NHLBI to limit to CDEs from them and notice that now I have the option to filter to specific projects and topics within NHLBI like sickle cell disease. And again, I can just take that filter off by clicking on the X beside it. The second piece of criteria that you can filter by is registration status and I'll scroll down to see that one. Those are below the collection options. Remember that registration status indicates how broadly a CDE is being recommended or used. If you can't find an endorsed CDE, check to see if any standard CDEs meet your criteria. A standard registration means that the CDE might have been developed by a standards development organization like LOINC, or vetted by some other recognized authority.

So I'll limit to standard CDEs by clicking on the box beside it, and now I have 24 results. And just glancing at the titles, these appear to be related to my topic of physical activity.

There's another way to find relevant results that I want to show you from here. So first I'll click on a CDE that I'm interested in. I'm going to choose the third one in our list titled "To what extent are you able to carry out your everyday physical activities such as walking, etcetera?" I'll click on that. First, I noticed that this does not include the blue banner indicating it's part of a bundle. So it's not a part of a bundle. And if I scroll down below the Permissible Values table, I get to this Related Content section with a tab that says Linked Forms. If the CDE appears on any forms, they'll be listed on this tab and here we have two. So this can be a good strategy for finding forms related to your topic if you find a CDE related to your topic. All right, let's pause again for any questions that have come in. Anything we can answer, Kate?

KATE: Perhaps we'll give folks a few seconds to see if they have some questions they'd like to put into chat, and if not, we'll have some time in a little while if you'd like to move on to the next section.

CATHERINE: Absolutely. Sounds good. Okay. Let me open the Repository back up. So next we're going to review for CDEs and you're struggling to find one related to your topic. So let's say you want to view CDEs that measure pain or have to do with pain in some way. I'm going to go back out to the Repository home page and again I'll switch to searching all CDEs and I'll just search for pain. So this time we get over 1000 results. On the one hand, that's great because it means that we have a lot of options for finding a relevant CDE. On the other hand, that's a lot of results to sort through. So take a minute to look around the search results page and consider how you might narrow down these results. And then let me know in the chat one way that you would narrow these results down and think about the strategies that we just discussed when we search for physical activity. So what's one thing you might do to narrow this result list down?

All right, I'm getting some answers already. Good. Someone says standard. Yes, we can limit to the standard registration status. Fantastic. Susan says limit by institution. Yeah, institution or I think you mean collection. Absolutely. So the list of institutions and projects that pop up, we can limit to a specific collection from them. Caitlyn says use more terms, absolutely. Or a more specific term, yes, we have not talked about that yet, but that is where this is headed. Excellent. Great. Let's review a couple of the strategies that you suggested. I'm going to pull up a slide with those on them. So yeah, these options are also the answer to #9 on your handout if you want to record them there to come back later. So you can try to limit to NIH Endorse CDEs, you can limit to a specific collection, or you can limit to standard under registration type. And another strategy that one of you mentioned that we haven't talked about yet is to get more specific with your search by adding additional terms. So for example, is there a type of pain or pain in a specific part of the body that you're concerned with like a limb? Is there a condition or a disease that the pain is associated with, like a fracture? Is there an activity or movement that you're trying to gauge pain during, like walking? You can add these terms to your search to see if a more specific CDE is available, so let's try that.

I'm going to go back to the Repository and this time I'll add walking to my search and I can add that to the search box at the top of the results page. So now I'm searching for pain walking and that limits my results to 23 results. So getting more specific with my search terms really help to focus my options. And keep in mind that you can use a combination of these strategies to further narrow down your results.

OK, let's do another search together maybe this time we want to find CDEs to record body mass index. So I can go back up to my search box at the top of the page. This time I'll type in Body Mass index. Notice that some results do start to auto populate, so if I see the title of a CDE that I want, I can click on it from there. For this example, I'm just going to run my search and see all of the results that I get. Yeah. So I get 22 results and within those results, we can probably find what we need. However, unlike our previous example with pain, when we got over 1000 results and we needed to narrow our focus, we might want to broaden the search a bit to make sure that we're seeing as many potential CDEs as possible for our topic. So one way to broaden our search is to consider any alternative terms or abbreviations or acronyms that could be used for your term. So some CDEs might use a different word to describe the same topic that you're searching for. So what's another term, an abbreviation or an acronym that someone could use instead of Body Mass Index? What do you think? Let me know in the chat.

Great. I'm already seeing a couple folks here say BMI. Yes. So BMI is a common acronym for Body Mass Index. So we can try adding that to our search. Maybe there are CDEs that use that instead. So one way to also search for BMI in addition to Body Mass Index is to use the word OR to connect those words in the search box and that will search the repository for CDEs that contain either term. So OR is the answer to #10 on your handout. So I'll go up to the search box, I have Body Mass Index, I'll add OR BMI and search and I get 48 results. So that's more than when I just searched for Body Mass Index.

I want to point out one more feature that can help you find more CDEs on your topic. So to do that, first I'm going to click on a CDE in my results list. I'll just click on the first one and I'm going to scroll down to that Related Content box. Again, we looked at linked forms earlier. This time we're going to look at the tab in the middle that says More like this. And when I click on that, a list of CDEs similar to the one that I'm viewing will appear. So this is a great feature if you find a CDE that's on your topic, but it's not quite what you need and you want to view other similar options, and that's the answer to #11 on your handout.

OK, we are going to transition to searching for forms, which works very similar to searching for CDEs. If you know the name of a specific form that you're looking for, you can search directly for it. So let's try that now. So I'm going to go back out to the Repository homepage and this time I'll click on the search Forms tab above the search box and I want to look for the emotional well-being form from the Functional Assessment of Chronic Illness Therapy System or FACIT. So I'm just going to search for Emotional well-being. That's the title of the form I'm looking for and we'll search for that. I see that my first result is from FACIT, the group that I'm looking for, so I'm going to click on that to see if it's what I'm looking for. Now, normally we would expect to see a

form here, but instead we see this message. We do not have permission to display this form due to copyright or licensing restrictions. For more information see the Copyright section below. And then if I just look right below that banner I see this copyright section and it reads statement: "Yes this form is licensed, copyrighted or otherwise restricted and we do not have permission to display it. This form is copyright protected and cannot be displayed. More information can be found at the provided link." And then it has a link to FACIT's website and the LOINC website. So this is a newer feature of the CDE-R. All forms will have a copyright status with a link to more information if available.

So your turn to look for a form and take a look at its copyright status. So this time, let's try looking for the BRICS Social Determinants of Health form, and it's on the screen there. But BRICS is spelled B-R-I-C-S, BRICS Social Determinants of Health. And once you've got it, copy and paste its copyright status into the chat, and then we'll take a look together.

All right. I see a couple folks here have gotten it. Wonderful. It's a long form, so you have to scroll. Great. Let's take a look at finding that form and copyright status together. So I'll go back to the repository and I'll go back out to the home page. I'm going to search within forms for the title BRICS Social Determinants of Health. I get one result from the NINR, so that's the form I'm looking for. Click on that to view the entire thing and then define that copyright status. I've got to scroll past the 63 questions that are part of this form and then I get to this general details section and it says "Copyrighted: No. This material is freely available without restriction." So I don't need to get any other permissions to use it.

All right, there's one more way to find CDEs and forms in the Repository which is browsing. So you can use the CDE and form buttons at the top of the home page screen to browse. So let me go back up to the top of the page and we can click on CDEs or Forms to browse. I'm going to click Forms and on this page I see the different collections with available forms that we can browse. So I'll select the NICHD to see what forms they have and now we see the forms from that collection. Notice that additional filters open up for more specific projects within this collection, like the NBSTRN Core. So if you're looking for a specific group of forms or a project, you can look there. If you want to browse CDEs it's very similar process except I'll click CDEs from the menu at the top and then I can browse the CDEs that are a part of each collection.

Okay your turn to try out browsing. So for this exercise you want to browse CDEs and tell me in the chat the name of one of the NEI CDE collections that you can browse in the Repository. So within the NEI there's two different CDE collections that you can browse. Tell me the name of one of those in the chat.

All right. Getting lots of good responses here. So yes, one of them is the LASIK Quality of Life collaboration project, and the other is eyeGENE. Excellent. So let's take a look at finding that together. I'm going to go back to the Repository and I want To browse NEI CDEs. So I want to make sure I'm on the Browse CDEs page, scroll down to NEI, click on them and then as we can

see here, they have two collections of CDEs that we can browse the LASIK Quality of Life Project and eyeGENE. And you can click on those to view the CDEs within those collections.

OK. The final feature I'm going to demonstrate is how to save CDEs and forms so that you can come back and find them when you need them later. So the Repository has a feature called My Boards where you can create a board which is kind of like a folder to store CDEs and forms that you need later or that you want to export. And My Boards is the answer to #12 on your handout. In order to [access My] Boards, you will need to be logged into your UTS account. And like I pointed out at the beginning of the training, you can sign up for a UTS account if you don't already have one. So let me first show you how to add a CDE to a board. To do that, I'll just find the CDE that I want and I can click on the pin icon beside its name. And then-- so what's happening here is that it actually timed out my UTS account login. So I'm going to pause my share real quick and log back in so that I can show you all what this looks like so it looks familiar when you do it on your own. So just one second. Okey doke. Here we go. Resume, share. OK, so again, to save it to a board, I'm just going to click the pin beside the CDE name and then I can either add it to an existing board by clicking on it or I can create a new board from that window. If I want to view all of the boards that I have, I just want to go up to the top of the page and click on My Boards from the menu across the top and then I can see the different boards that I've created. So I have three. Notice that two of them are for CDEs and one is for forms. You can't save them on the same board, so you'll need to make separate boards for each type. And I'm going to click on my NEI CDEs board so that you can just see what this looks like when they are all on a board together. And then you have your export options here as well. All right. At this point, I'm going to ask Kate to put the handout answer key in the chat so that you'll have that if you want to review any of the answers that you missed. And then we will start to wrap up with any remaining questions that have come in. Kate, anything Robin and I can answer.

KATE: Yes, a few questions have come in. We're going to start with this one. **Back when we were searching for CDEs, both Deb and Susan noted that on the results page, you can see the number of results in each collection. But when there are NIH-endorsed CDEs in the results, the filter does not show the number of results. Robin, would you like to comment on that?**

ROBIN: I think that's a great suggestion and I would like to thank our audience for making it. I think it's honestly just an oversight. That's one of the newer search features that we added last year and I think we just neglected to put the number in there. But that's always really helpful, I know, to be able to see how many results are going to be within a particular filter. So I'm making a note of that and we'll see if we can get that added.

KATE: Wonderful. Thanks, Robin. All right, the next question, **Emir would like to know why the CDE-R does not resolve synonyms automatically and will that be added.**

ROBIN: Okay, I read this question and I'm not sure what you mean by resolve automatically. I will say that we use Elasticsearch for our search and Elasticsearch has its own built-in synonyms. So you will actually notice some synonyms being used in your search terms from time to time, if

you look at what you've entered versus what's actually being retrieved, like depression and depressing, or things like that. That said, we are also this year going to be exploring using terminology to categorize and group CDEs that have similar meanings and are about similar things. So that's probably going to help with dealing with the number of synonyms in the Repository. I hope that helps.

KATE: Thank you. Emir also asks, **if I have a UMLS license and I'm logged into the UTS, will the CDE-R allow me to view the restricted forms?**

ROBIN: No. The forms that are restricted and not displayed, we simply don't have permission to display. They might have a fee associated with it, or there might be some other issue involved with the distribution of it. So the UTS license doesn't help with any of those. The UTS license will let you see, I think she mentioned this in the course, but it will let you see some of the terminologies that are hidden. If you're not logged in, you might not be able to see all the permissible value or concept codes. If you're logged in, you would be able to see those codes. That's what that will reveal to you. But, the copyrighted and restricted forms are just, restricted for everybody.

KATE: OK, thank you. Deb asks, **is there a filter for forms that are not copyrighted?**

ROBIN: No, there is not, but that's another great idea that I've made a note of. So thank you Deb for that. That is something I've actually-- I've thought about that before, but we've not included that yet, but I think it's a feature we'll want to add soon. Thank you.

KATE: Wonderful. **I also wanted to note that Ally provided a tip in chat about finding copyright information. Ally was using Ctrl+F with her browser for the term copyright to jump to that section of the page.** Thanks Ally. Another question came in while we were talking. Ariel would like to know **NIMH now requires certain CDEs for grantees, but I don't see most of them here. Is the idea that all required NIH CDEs will eventually be available here?**

ROBIN: Ariel, that's a great question. When you say all required NIH CDEs, I don't know about that. I will say that what we definitely want to have here, are CDEs that could be used across many NIH projects. You know that there's different topics, and diseases, domains that sort of cross the boundaries between the ICs, and any CDEs that might be used like globally or you know across different ICs like that we definitely wanted them. We encourage those groups to submit those CDEs to the repository for publication. I know that there can be many more very specialized CDEs that, may be a lot less common, maybe only used, really within one program or something. And again if the institute that hosts those doesn't have their own platform for making them available, the NIH CDE Repository is here, and we would certainly welcome that submission and make them available here in our Repository as well.

KATE: Okay, thank you. And Caitlin had a follow up just expressing surprise that the NIMH CDEs are not included.

ROBIN: I will say, the NIH CDE Governance Committee is currently reviewing a submission, I believe. I don't want to say the wrong thing, but I think it's from NIMH and NINR and it's the SchARe CDEs and I don't remember what SchARe stands for off the top of my head, but there's a lot of like social determinants of health, I think, and that kind of thing involved. And so I know that NIMH has at least made like 1 submission to the Governance Committee for publishing in the Repository. So you know things are coming there. As I said earlier like on a rolling basis we are accepting these and reviewing and endorsing and just hopefully building up the collection overtime.

KATE: Okay great. So hopefully the ones you're looking for are on the way. One follow up from Emir, **just clarifying Emir's question about synonyms. Emir says, I mean when you search BMI, it will understand that it's body mass index and vice versa.**

ROBIN: Ah, I see. Yeah, we've talked about that a bit. I would say it's not a high priority for us at this time. I mean understanding what somebody means when they type something wrong is, you know, not that straightforward, I think, according to our developers anyway, and the conversations I've had with them. So I know it's a really useful service that a lot of the larger search engines provide and other websites, but that's not something we have at this time. Yeah.

KATE: OK. Thank you. I see no other questions in chat at this time. So back to you Catherine.

CATHERINE: Okay, great. So let us wrap up and I want to review how to get help and find out about updates to the Repository. So first, there's a new NIH CDE-R News Listserv that you can join to keep up with the latest updates and features, and that link is on the handout for you. And then also, if you're in the Repository and you hover over the Help menu, you'll see four options. The Guides page offers step by step instructions for conducting many of the actions in the Repository, including those demonstrated today. The New Features page includes announcements and news about the repository. The Resources page has links to additional training, information about APIs, and examples of CDEs being used in biomedical research. And you can use the Contact Us page to send your questions directly to the NLM.