General information

OMB # 0925-0678 Expiration Date: 08/2016

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Background

The NINDS Common Data Elements (CDE) Project was launched in 2005 with the primary goal to develop data standards for clinical research involving neurological disorders so that data are captured consistently across different studies. In addition to one set of general CDEs that are applicable to all neurology studies, 18 disease-specific sets of CDEs have been developed through the program. NINDS is interested in getting feedback from the community based on their experience with CDEs so that we can assess how well the current program is meeting the needs of clinical researchers.

Why you should participate

The information we collect from this survey will help give NINDS a clearer picture of the research community's perspectives on the current NINDS CDEs. This survey will help define future strategies related to the development and maintenance of NINDS CDEs, and identify opportunities to enhance the project's impact on clinical research for neurological disorders. Participation in this survey is voluntary and should only take 10 minutes to complete.

| the project's impact on clinical research for neurological disorders. Participation in this sur voluntary and should only take 10 minutes to complete. | | | |
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| * | 1. What neurological disease or condition best describes the primary focus of your clinical research? | | |
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| * 2. Have you used any NINDS CDEs or served on any committees related to the development of NINDS CDEs? | | | | |
|---------------------------------------------------------------------------------------------------------|--|--|--|--|
| I have used NINDS CDEs and was involved in NINDS CDE development | | | | |
| I have used NINDS CDEs | | | | |
| I served on an NINDS CDE development working group | | | | |
| I have no experience with NINDS CDEs | | | | |
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Participants with NINDS CDE experience & development

* 3. Below is a list of NINDS CDEs that are currently available to the research community. Please indicate which set(s) are relevant to your area(s) of research, and which set(s) you have used. You do not need to make a selection for those that are not relevant to your research area.

| | relevant, but have <u>not</u> used | relevant and have used |
|----------------------------------|------------------------------------|------------------------|
| General | | |
| Amyotrophic Lateral Sclerosis | | |
| Epilepsy | | |
| Friedreich's Ataxia | | |
| Headache | | |
| Huntington's Disease | | |
| Mitochondrial Disease | | |
| Multiple Sclerosis | | |
| Neuromuscular Diseases | | |
| Congenital Muscular Dystrophy | | |
| Myasthenia Gravis | | |
| Spinal Muscular Atrophhy | | |
| Parkinson's Disease | | |
| Spinal Cord Injury | | |
| Stroke | | |
| Traumatic Brain Injury | | |
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| * 4. V | What was your role in the research study or studies that used CDEs? Check all that apply. |
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| | Trial PI |
| | Site PI |
| | Co-investigator |
| | Colleague/Collaborator |
| | Project Coordinator |
| | Data management role |
| | Other (please specify) |
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| * 5. V | What type of clinical study did you use NINDS CDEs with? |
| | Observational / cohort study (including epidemiology, genetics, biomarkers, etc) |
| | Human subjects basic research study (e.g. small hypothesis-generating studies not classified as clinical trials) |
| | Exploratory clinical trials (including Phase I/II trials, or other early stage clinical trial) |
| | Phase III clinical trial |
| | Other (please specify) |
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| * 6. H | How did you become aware of the NINDS CDEs? |
| | Scientific meeting |
| | NINDS staff/Program Director |
| | NINDS website |
| | NLM website |
| | NINDS FOA |
| | Other (please specify) |
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| | Other (please specify) |

| No yes, what were they? (e.g. difficulty incorporating necessary forms, lacked important data elements, increased effort to develor datases) One goal of the CDE program is to provide data collection tools to facilitate efficient study start up. Discress to the NINDS CDEs make it easier to set up the data collection processes for your study? Yes No ease explain whether/how the CDE tools influenced efficiency of study start-up processes: O. How would you rate the overall level of effort/burden associated with using the CDEs in your research udy, as compared to your previous experiences with non-CDE studies? More effort, highly More effort but manageable Similar amount of effort Less effort | No yes, what were they? (e.g. difficulty incorporating necessary forms, lacked important data elements, increased effort to develop tabases) One goal of the CDE program is to provide data collection tools to facilitate efficient study start up. Did coss to the NINDS CDEs make it easier to set up the data collection processes for your study? Yes No ease explain whether/how the CDE tools influenced efficiency of study start-up processes: O. How would you rate the overall level of effort/burden associated with using the CDEs in your research udy, as compared to your previous experiences with non-CDE studies? More effort, highly burdensome More effort, burdensome More effort but manageable Similar amount of effort Less effort | | | | | |
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| burdensome More effort, burdensome manageable Similar amount of effort Less effort | burdensome More effort, burdensome manageable Similar amount of effort Less effort | | | | | |
| Comments: | | 10. How would you | rate the overall level of eff | fort/burden associ | ated with using the CDEs | in your research |
| Comments: | Comments: | 10. How would you study, as compared | rate the overall level of eff to your previous experien | fort/burden associ aces with non-CDI More effort but | ated with using the CDEs E studies? | |
| | | 10. How would you study, as compared | rate the overall level of eff to your previous experien | fort/burden associ aces with non-CDI More effort but | ated with using the CDEs E studies? | |
| | | 10. How would you study, as compared More effort, highly burdensome | rate the overall level of eff to your previous experien | fort/burden associ aces with non-CDI More effort but | ated with using the CDEs E studies? | |

| 11. Do you agree that N | INDS CDEs are or | could be a valuable res | source for the neuro | science community? |
|--------------------------------------------------------------------------|----------------------|--------------------------|----------------------|-------------------------|
| Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
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| Comments: | | | | |
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| 12. The process of achieves arch is challenging. | • | | | |
| process was for initial d | . • | • | | molerit do you reel the |
| Very inefficient | Inefficient | Neutral opinion | Efficient | Highly efficient |
| | | | | |
| Comments: | | | | |
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| determine when a topic | gets updated? | | | |
| 14. Do you have any ad | lditional suggestion | s for ways to improve th | ne CDE developme | nt or review process? |
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| 15. Broad awareness ar of common data elementield, and do you believe | nts. Do you believe | there is broad awarene | ss of the NINDS C | <u>-</u> |
| nield, and do you believe | e there is wide buy- | -in of the concept? why | /Wily Hot? | |
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Participants with NINDS CDE experience

* 16. Below is a list of NINDS CDEs that are currently available to the research community. Please indicate which set(s) are relevant to your area(s) of research, and which set(s) you have used. You do not need to make a selection for those that are not relevant to your research area.

| | relevant, but have <u>not</u> used | relevant and have used |
|----------------------------------|------------------------------------|------------------------|
| General | | |
| Amyotrophic Lateral Sclerosis | | |
| Epilepsy | | |
| Friedreich's Ataxia | | |
| Headache | | |
| Huntington's Disease | | |
| Mitochondrial Disease | | |
| Multiple Sclerosis | | |
| Neuromuscular Diseases | | |
| Congenital Muscular Dystrophy | | |
| Myasthenia Gravis | | |
| Spinal Muscular Atrophhy | | |
| Parkinson's Disease | | |
| Spinal Cord Injury | | |
| Stroke | | |
| Traumatic Brain Injury | | |
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| * 17. | What was your role in the research study or studies that used CDEs? Check all that apply. |
|-------|------------------------------------------------------------------------------------------------------------------|
| | Trial PI |
| | Site PI |
| | Co-investigator Co-investigator |
| | Colleague/Collaborator |
| | Project Coordinator |
| | Data management role |
| | Other (please specify) |
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| * 18. | What type of clinical study did you use NINDS CDEs with? |
| | Observational / cohort study (including epidemiology, genetics, biomarkers, etc) |
| | Human subjects basic research study (e.g. small hypothesis-generating studies not classified as clinical trials) |
| | Exploratory clinical trials (including Phase I/II trials, or other early stage clinical trial) |
| | Phase III clinical trial |
| | Other (please specify) |
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| * 19. | How did you become aware of the NINDS CDEs? |
| | Scientific meeting |
| | NINDS staff/Program Director |
| | NINDS website |
| | NLM website |
| | NINDS FOA |
| | Other (please specify) |
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| No as, what were they? (e.g. difficulty incorporating necessary forms, lacked important data elements, increased effort to develop abases) One goal of the CDE program is to provide data collection tools to facilitate efficient study start up. Discuss to the NINDS CDEs make it easier to set up the data collection processes for your study? Yes No asse explain whether/how the CDE tools influenced efficiency of study start-up processes: How would you rate the overall level of effort/burden associated with using the CDEs in your research dy, as compared to your previous experiences with non-CDE studies? More effort, highly burdensome More effort, burdensome manageable Similar amount of effort Less effort | | | | | |
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| es, what were they? (e.g. difficulty incorporating necessary forms, lacked important data elements, increased effort to develop abases) One goal of the CDE program is to provide data collection tools to facilitate efficient study start up. Discuss to the NINDS CDEs make it easier to set up the data collection processes for your study? Yes No asse explain whether/how the CDE tools influenced efficiency of study start-up processes: How would you rate the overall level of effort/burden associated with using the CDEs in your research day, as compared to your previous experiences with non-CDE studies? More effort, highly burdensome More effort, burdensome Similar amount of effort Less effort | - | areau rannagee to denig in | | | |
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| More effort, highly burdensome More effort, burdensome More effort but manageable Similar amount of effort Less effort | , | how the CDE tools influenced ef | fficiency of study start | -up processes: | |
| More effort, highly burdensome More effort, burdensome More effort but manageable Similar amount of effort Less effort | | how the CDE tools influenced ef | fficiency of study start | -up processes: | |
| burdensome More effort, burdensome manageable Similar amount of effort Less effort O O O O | ase explain whether/l | rate the overall level of eff | fort/burden associ | ated with using the CDEs | in your research |
| | . How would you ady, as compared | rate the overall level of eff | fort/burden associ nces with non-CDI | ated with using the CDEs | in your research |
| mments: | . How would you lidy, as compared | rate the overall level of eff to your previous experien | fort/burden associ nces with non-CDI More effort but | ated with using the CDEs E studies? | |
| | ase explain whether/l . How would you lidy, as compared More effort, highly | rate the overall level of eff to your previous experien | fort/burden associ nces with non-CDI More effort but | ated with using the CDEs E studies? | |
| | . How would you udy, as compared More effort, highly burdensome | rate the overall level of eff to your previous experien | fort/burden associ nces with non-CDI More effort but | ated with using the CDEs E studies? | |
| | . How would you udy, as compared More effort, highly burdensome | rate the overall level of eff to your previous experien | fort/burden associ nces with non-CDI More effort but | ated with using the CDEs E studies? | |
| | ease explain whether/l | rate the overall level of eff to your previous experien | fort/burden associ nces with non-CDI More effort but | ated with using the CDEs E studies? | |
| | ase explain whether/les. How would you ady, as compared More effort, highly burdensome | rate the overall level of eff to your previous experien | fort/burden associ nces with non-CDI More effort but | ated with using the CDEs E studies? | |
| | ase explain whether/les. How would you ady, as compared More effort, highly burdensome | rate the overall level of eff to your previous experien | fort/burden associ nces with non-CDI More effort but | ated with using the CDEs E studies? | |

| Strongly Disagree | Disagree | Undecided | Agree | Strongly Agree |
|-------------------|----------|-----------|-------|----------------|
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| nments: | | | | |
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| NINDS Common Da | ata Elements (Cl | DE) Survey | | |
|--------------------------------------------------|-----------------------------------------|----------------------------------------------------------------------------|----------------------|-----------------------|
| Participants involved | d in NINDS CDE | development | | |
| | | | | |
| research is challenging | g. Keeping in mind t | consensus on common d he complex nature of su CDEs for your research | ch an effort, how ef | |
| Very inefficient | Inefficient | Neutral opinion | Efficient | Highly efficient |
| | | | | |
| 20 Hadaka dha 005 | | | | |
| of the science. How fre | equently do you thin | ocess for ensuring the CI | • | |
| , • | equently do you thin | - | • | |
| of the science. How fre | equently do you thin | - | • | |
| of the science. How fre determine when a topi | equently do you thin c gets updated? | - | ıld be reviewed and | d what factors should |
| of the science. How fre determine when a topi | equently do you thin c gets updated? | k the NINDS CDEs shou | ıld be reviewed and | d what factors should |

Experience with non-NINDS CDEs

| | - | include topic-specific CDEs from other NIH arch activities (e.g. FDA CDISC). Please |
|-----------------------------------|--------------------------------|-------------------------------------------------------------------------------------|
| I have not used other CDEs | | |
| Asthma CDEs | | |
| cLBP | | |
| EDRN | | |
| eyeGENE | | |
| GRDR | | |
| Neuro-QOL | | |
| NIDA EHR | | |
| NIH Toolbox | | |
| PhenX | | |
| PROMIS | | |
| CDEs provided by a society or fou | ndation | |
| Other (please specify) | | |
| * 30. Are you likely to use NINDS | CDEs in future studies (if ava | ilable for the particular topic under study)? |
| | Yes | No |
| NINDS-funded studies: | | |
| Non-NINDS funded studies: | \bigcirc | |
| Why or why not? | | |
| | | |
| | | |
| | | |

| * 31. In general, do you think CDEs have the potential to (check all that apply): | | | | |
|---------------------------------------------------------------------------------------------------|--|--|--|--|
| improve data quality | | | | |
| enable data sharing | | | | |
| facilitate more meta-analyses | | | | |
| lead to improved quality or validity in systematic reviews | | | | |
| none of the above | | | | |
| Other (please specify) | | | | |
| | | | | |
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| 32. Are there any comments or suggestions you would like to provide to help NINDS improve the CDE | | | | |
| program's processes, products, or overall impact on the research community? | | | | |
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| No | No experience with NINDS CDEs | | | | |
|-------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|--|--|--|
| | | | | | |
| * 33 | . What was your reason for not using NINDS CDEs? Check all that apply. | | | | |
| | not aware of them | | | | |
| | no disease specific CDEs available for field of study | | | | |
| | inconvenient | | | | |
| | did not capture data needed | | | | |
| | Other (please specify) | | | | |
| | | | | | |
| | | | | | |
| ¥ 0.4 | Llave you used any other (non NINDC) CDEs2 Everelles include tonic are sife CDEs from all and All I | | | | |
| | . Have you used any other (non-NINDS) CDEs? Examples include topic-specific CDEs from other NIH stitutes, or data elements that are required for specific research activities (e.g. FDA CDISC). Please | | | | |
| ma | ark all that you have used. | | | | |
| | I have not used other CDEs | | | | |
| | Asthma CDEs | | | | |
| | clBP | | | | |
| | EDRN | | | | |
| | eyeGENE | | | | |
| | GRDR | | | | |
| | Neuro-QOL | | | | |
| | NIDA EHR | | | | |
| | NIH Toolbox | | | | |
| | PhenX | | | | |
| | PROMIS | | | | |
| | CDEs provided by a society or foundation | | | | |
| | Other (please specify) | | | | |
| | | | | | |
| | | | | | |

| 35. Are you likely to use NINDS CDEs in future studies (if available for the particular topic under study)? | | | |
|-------------------------------------------------------------------------------------------------------------|---------------------------------|------------------------------------------------------|--|
| | Yes | No | |
| NINDS-funded studies: | | | |
| Non-NINDS funded studies: | | | |
| hy or why not? | | | |
| | | | |
| | | | |
| 6. In general, do you think CDE | s have the notential to (check | all that annly): | |
| improve data quality | io navo uno potentiar to (onook | an did apply). | |
| enable data sharing | | | |
| facilitate more meta-analyses | | | |
| lead to improved quality or validity | in evetamatic reviews | | |
| none of the above | iii systematic reviews | | |
| | | | |
| Other (please specify) | | | |
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| 7. Are there any comments or strogram's processes, products, | | provide to help NINDS improve the CDE rch community? | |
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