The PhenX Toolkit: Updated Substance Use, Use Disorders, and Recovery Collections and an Expanded Cardiovascular Domain

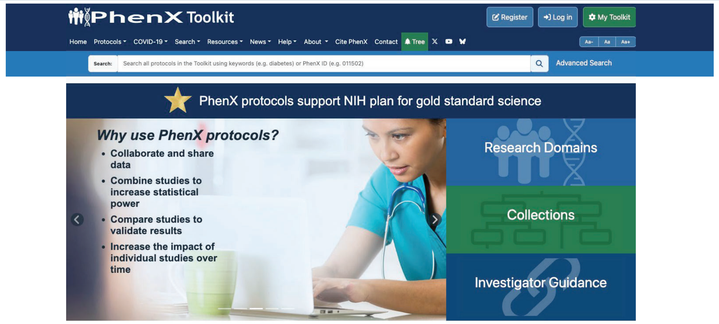
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PhenX
consensus measures for Phenotypes and eXposures

https://www.phenxtoolkit.org/

What Is the PhenX Toolkit?



PhenX Toolkit

The *PhenX (consensus measures for Phenotypes and eXposures) Toolkit* is a web-based catalog of recommended measurement protocols of phenotypes and exposures suitable for inclusion in genomic, clinical, and translational research studies with human participants.

https://www.phenxtoolkit.org/

The Web-based PhenX Toolkit (consensus measures for Phenotypes and eXposures, https://www.phenxtoolkit.org/) provides a catalog of standard protocols and associated tools (e.g., Data Collection Worksheets and Data Dictionaries) to help investigators improve the consistency of data collection and identify opportunities for collaboration.

The PhenX Toolkit is:	The PhenX Toolkit is not:
• A catalog of recommended measurement protocols	• A data repository
• A creation of the scientific community via a consensus-based process led by subject-matter experts	• A restricted forum (investigators can use other measurement protocols)
• A free Web-based resource	• A new set of standards
	• A new ontology of phenotypes and exposures

New Toolkit Features

- Digital object identifiers (DOIs) for all PhenX protocols via the "Cite This Protocol" and "Cite My Toolkit" functions
- Improved navigation, MyToolkit, Advanced Search, and About pages
- Feedback tool

PhenX Substance Use and Recovery Protocols

- The Substance Use and Recovery Working Group (WG), co-chaired by Anne Buu (UTHealth Houston) and John Kelly (Harvard Medical School), added 30 new protocols to the PhenX Toolkit in May 2025.
- Protocols address medical cannabis use, polysubstance use, and substance use recovery.
- The WG updated the Substance Use, Use Disorders, and Recovery (SUR) Collections and added a new Substance Use Recovery Specialty Collection.
- Funded by NIDA through an administrative supplement to PhenX.

PhenX Protocol Name	Protocol Source
12-Step Group Participation	Multidimensional Mutual-Help Activity Scale (MM-HAS)
Alcohol and Cannabis Simultaneous Use	Alcohol and Cannabis Simultaneous Use Scale (ACSUS)
Assessment of Cannabis Use Disorder	Cannabis Use Disorder Identification Test–Revised (CUDIT-R)
Biochemical Validation of Cannabis Consumption	Biochemical Validation of Cannabis Consumption
Brief Assessment of Social Network Characteristics	Kaskutas et al., 2002[a]
Cannabis Products, Types, and Modes of Use	International Cannabis Policy Study Survey
Client Satisfaction	Client Satisfaction Questionnaire-8 (CSQ-8)
Co-use of Opioids With Other Drugs and Overdose Risk	Opioid Overdose Risk Behavior Scale (ORBS-2)
Comprehensive Interviewer-Administered Assessment of Social Network Characteristics	Important People Drug and Alcohol (IPDA) Interview
Expectancies for Medical Cannabis Use	The Cannabis Effects Expectancy Questionnaire–Medical (CEEQ-M)
Future Service Needs–Self-Help Involvement	Global Appraisal of Individual Needs–Initial (GAIN-I)
General Cannabis Use	International Cannabis Policy Study Survey
Happiness With Recovery	Happiness with Recovery Questionnaire
Medical Cannabis Card Status	International Cannabis Policy Study Survey
Medical Cannabis Provider-Patient Communication	National Cancer Institute (NCI) Supplement Cannabis Core Measures Questionnaire
Motives–Alcohol, Tobacco, and Other Substances– Cannabis	Comprehensive Marijuana Motives Questionnaire (CMMQ) Short Form
Motives for Using Medical Cannabis	International Cannabis Policy Study (ICPS)
Multidimensional Assessment of Recovery Capital	Multidimensional Inventory of Recovery Capital (MIRC)
Mutual-Help Group Involvement and Treatment Attendance	Peer Alternatives for Addiction (PAL) Mutual-Help Group Involvement and Treatment Attendance Questions
Patterns of Substance Use–Alcohol and/or Drug Use	Timeline Followback–Alcohol Use
Patterns of Substance Use–Calendar-Based Method for Detailed Cannabis Use	Petrilli et al., 2024[b]
Polysubstance Use Frequency–Past Year	Tobacco, Alcohol, Prescription Medication, and Other Substance Use (TAPS-I)
Post-acute Withdrawal Signs and Symptoms	Symptom Checklist-90 (SCL-90)
Post-acute Withdrawal Signs and Symptoms–Craving	Penn Alcohol Craving Scale (PACS)
Recovery Identification	Kaskutas et al., 2015[c]
Social Relationship Quality	NIH Toolbox Adult Relationship Scale
Sources of Cannabis	International Cannabis Policy Study Survey
Substance Use Goal	Thoughts About Abstinence (TAA) Scale
Unidimensional Assessment of Recovery Capital	Brief Assessment of Recovery Capital (BARC-10)
Use of Treatment and Recovery Support Services	Kelly et al., 2017[d]

Complete protocol sources are available in the SUR Collections: https://www.phenxtoolkit.org/sub-collections/view/43

[a] Kaskutas, L. A., Bond, J., & Humphreys, K. (2002). Social networks as mediators of the effect of Alcoholics Anonymous. *Addiction, 97*(7), 891-900. https://doi.org/10.1046/j.1360-0443.2002.00118.x

[b] Petrilli, K., Lawn, W., Lees, R., Mokrysz, C., Borissova, A., Ofori, S., Trinci, K., Dos Santos, R., Leitch, H., Soni, S., Hines, L. A., Lorenzetti, V., Curran, H. V., & Freeman, T. P. (2024). *Addiction (Abingdon, England),* 119(4), 772-783. https://doi.org/10.1111/add.16405

[c] Kaskutas, L. A., & Ritter, L. A. (2015). Consistency between beliefs and behavior regarding use of substances in recovery. *SAGE Open, 5*(1). https://doi.org/10.1177/2158244015574938

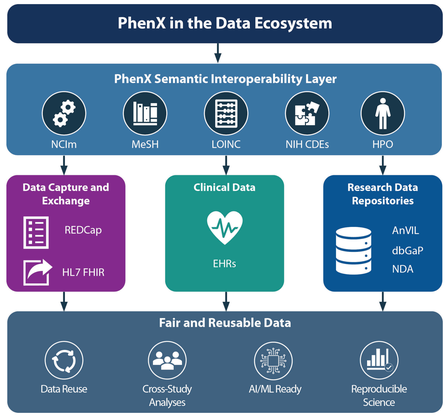
[d] Kelly, J. F., Bergman, B. G., Hoeppner, B. B., Vilsaint, C., & White, W. L. (2017). Prevalence and pathways of recovery from drug and alcohol problems in the United States population: Implications for practice, research, and policy. Drug and Alcohol Dependence, 181, 162-169. https://doi.org/10.1016/j.drugalcdep.2017.09.028

Cardiovascular Domain

- Originally added to the Toolkit in 2009, the Cardiovascular Domain is currently being reviewed.
- In April 2026, a new WG was convened to update the Cardiovascular Domain with new protocols related to cardiovascular disease. The WG is co-chaired by Matthew Allison (UCSD) and Mark Weiner (Regeneron).
- The WG recommended 8 measures, 15 new protocols, and 13 supplemental information items for community outreach anticipated in November 2026 and Toolkit release in 2027.

Cardiovascular Domain Proposed New Measures
Aortic Dissection
Coronary Heart Disease
Genetic Testing for Heritable Thoracic Aortic Disease
Heart Failure
Hypertrophic Cardiomyopathy
N-terminal Pro-brain Natriuretic Peptide (NT-proBNP)
Peripheral Arterial Disease
Peripheral Venous Disease

PhenX in the Data Ecosystem



The PhenX Toolkit is complementary to and collaborative with related efforts, standards, data repositories, and other biomedical resources supporting a trans-NIH data ecosystem. PhenX protocols are available as REDCap instrument .zip files, allowing import into the REDCap application for web-based deployment of support for data collection. PhenX protocols are associated with biomedical standards, including LOINC, HPO, and CDEs, to help users represent, find, and exchange data. PhenX protocols are linked to variables in data repositories (e.g., dbGaP, NDA, AnVIL) to help users discover opportunities for cross-study analyses. These ongoing collaborations support the NIH Data Management and Sharing Policy and help PhenX users collect, find, share, and exchange data. The PhenX Toolkit supports FAIR principles (Findable, Accessible, Interoperable, Reusable) and increases the impact of individual studies.

AI = Artificial Intelligence; AnVIL = Genomic Data Science Analysis, Visualization, and Informatics Lab-space; EHRs = Electronic Health Records; HL7 FHIR = Fast Healthcare Interoperability Resources; HPO-Human Phenotype Ontology; LOINC = Logical Observation Identifiers Names and Codes; MeSH = Medical Subject Headings; ML = Machine Learning; NCIm = National Cancer Institute Metathesaurus; NIH CDEs = National Institute of Health Common Data Elements; NDA = NIMH Data Archive; REDCap = Research Electronic Data Capture

How to Get Involved

If you would like to receive e-mail notifications and updates about the PhenX Toolkit, please register here to create a PhenX Toolkit user account: https://www.phenxtoolkit.org/users/register

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