



## Healthy Oregon Project (HOP)

### Data Catalog

The Healthy Oregon Project (HOP) is a secure repository managed by OHSU that stores self-reported survey answers as well as associated human specimens, such as blood, tissue, and body fluids like saliva, for use in authorized future research studies. Access to this repository is carefully controlled to ensure it is only used by qualified scientists engaged in legitimate research. This study aims to build a cohort of individuals motivated to contribute to health research, serving as a trusted resource for scientists looking for participants for future research studies.

Review our catalog below to learn what type of data we collect or store. A data dictionary is made available upon request. Feel free to inquire about any specifics in our [HOP Request Form](#).

*Please note: Aggregate data can be made available upon request for grant and preparation to research. Individual-level information will require IRB determination and review by our data access committee.*

## Legend

● (red dot) = This form, survey, or feature is being modified on the application soon.

Blue text = Any data limitations.

Forms or surveys				
Type of data we collect	Data source (Form or Survey name on app)	# of survey or form responses (estimate)	Eligible participants	How often it's administered
<ul style="list-style-type: none"> <li>a. Contact information</li> <li>b. Demographics &amp; identities (age at sign-up, date of birth, location, race/ethnicity, sex at birth, self-described gender)</li> </ul>	Eligibility & Account sign-up	52,041	All HOP participants	One-time; editable unlimited number of times ●
<ul style="list-style-type: none"> <li>a. Educational attainment, marital status, employment status, health insurance coverage</li> <li>b. Height/weight</li> <li>c. History of cancer</li> <li>d. Health information seeking behaviors</li> <li>e. Rating health information access via statements</li> <li>f. Rating generalized statements on beliefs on cancer and awareness of risk of cancer</li> </ul>	"Cancer Risks and Beliefs" (UCAN Oregon) survey ●	11,460	All HOP participants	One-time ●; only new data if a participant has updated information

g. History of use & current use of tobacco h. Colorectal cancer screening history i. Breast cancer screening history j. Cervical & HPV screening history k. Lung cancer screening history				
a. History of use & current use of tobacco b. History of use & current use of alcohol	“Behaviors” survey	36,165	All HOP participants	One-time ●
a. Rating generalized statements on beliefs on cancer and awareness of risk of cancer and fatalism	“Cancer Beliefs” survey	10,256	All HOP participants	One-time
a. Cancer diagnosis(es) type(s) b. Familial history of cancer (by family member)	“Cancer History” survey	32,911	All HOP participants	Every 6 months
a. Colorectal cancer history (self & familial history)	“Colorectal History” survey	28,332	All HOP participants	One-time
a. Height/weight b. Water consumption habits c. Dietary/nutritional habits d. Exercise habits e. Sleeping habits f. Chronic disease diagnosis(es) (list to choose from)	“Lifestyle” survey	27,811	All HOP participants	One-time
a. Rating statements to assess stress with feedback scoring available	“Perceived Stress Scale” survey	26,356	All HOP participants	One-time

a. Rating statements to assess impulse control with feedback scoring available	“Impulsivity Scale” survey	21,360	All HOP participants	One-time
a. Experiences and concerns with air quality b. Experience with air quality information c. Community services for air quality d. Preparation for air quality	“Adapting to Wildfire Smoke” survey	3,150	All HOP participants	One-time
<b>Cohort-specific forms or surveys</b>				
Type of data we collect	Data source (Form or Survey name on app)	# of survey or form responses (estimate)	Eligible participants	How often it’s administered
a. Level of education b. Assessment of understanding of negative genetic testing results of cancer risk c. Feedback on experience with receiving negative genetic test results of cancer risk d. Assessment of motivation on genetic testing of cancer risk	“Result Feedback” survey (result = HOP genetic testing result)  <b>Only participants who completed genetic screening prior to it pausing in early 2025 received or will receive this survey.</b>	518	HOP participants who completed genetic testing and received a <i>positive</i> result	One-time
		10,278	HOP participants who completed genetic testing and received a <i>negative</i> result	

<ul style="list-style-type: none"> <li>a. Exposure history</li> <li>b. Respiratory history (e.g., cough, phlegm, wheeze, breathlessness)</li> </ul>	Wildfire Smoke in Oregon (WSO) Study – Enrollment survey	65	(English-only) Wildfire Smoke in Oregon (WSO) study cohort	One-time
<ul style="list-style-type: none"> <li>a. Rating statements to assess wellbeing (e.g., social connection, diet, managing stress, physical activity, sleep hygiene)</li> </ul>	WSO Study – Wellbeing survey	<b>Enrollment pending</b>		Two times
<ul style="list-style-type: none"> <li>a. Wildfire smoke symptoms (e.g., wheezing, coughing)</li> </ul>	WSO Study – Daily Symptoms survey	<b>Enrollment pending</b>		Two, 6-day periods
<ul style="list-style-type: none"> <li>a. Demographics</li> <li>b. Testing</li> <li>c. Social distancing &amp; socializing behaviors</li> <li>d. Health and medical care</li> <li>e. Dietary/nutritional habits</li> <li>f. Alcohol, tobacco, and marijuana use</li> <li>g. Cancer and cancer screening (breast, colorectal, cervical, oral)</li> </ul>	“COVID-19 and You” survey  <b>No longer administered on the app.</b>	2,158	<b>N/A</b>	<b>N/A</b>

## Clinical repository

		<b>Genetic data available</b>	<b>Annual survey data (Year 1 and 2)</b>	<b>Patient navigator data</b>
<b>Type of data collected</b>	Concentrated DNA	<p>Our cohort includes participants with the following genetic mutations:</p> <p>APC, ATM, BAP1, BRCA1, BRCA2, BRIP1, CDH1, CDKN2A, CHEK1, CHEK2, LDLR, MEN1, MTF, MLH1, MSH2, MSH6, MUTYH, NBN, PALB2, PMS2, PTEN, RAD51C, RAD51D, RET, TP53, TSC1, TSC2</p>	<ol style="list-style-type: none"> <li>1. Cancer screening and interventions</li> <li>2. Personal cancer history &amp; Family genetic risk</li> <li>3. Lifestyle</li> <li>4. Physical attributes</li> <li>5. Physical activity</li> <li>6. Diet</li> <li>7. Demographics</li> </ol>	<ol style="list-style-type: none"> <li>1. Genetic variant</li> <li>2. Access to medical care</li> <li>3. Family history of cancer</li> <li>4. Insurance type</li> <li>5. Family notification of genetic variant</li> <li>6. Economic insecurity (limited access to: food, utilities, transportation, clothing, housing, medical care, medicine)</li> </ol>
<b>Number available (estimate)</b>	32,461	<ul style="list-style-type: none"> <li>• Positive: 1,325</li> <li>• Negative: 26,632</li> </ul>	<ul style="list-style-type: none"> <li>• Year 1: 119</li> <li>• Year 2: 102</li> </ul>	1,385