

FY21 ANNUAL REPORT







FY21 at a glance

active projects

4,661

unique twins participated in a study

48

new twin pairs enrolled in the Registry

<u>12</u>

new peer-reviewed publications

About the Registry

The Washington State Twin Registry (WSTR) is administratively housed in the Department of Nutrition and Exercise Physiology, Elson S. Floyd College of Medicine, Washington State University Spokane.





The WSU Institutional Review Board (IRB) is responsible for the review and approval of all research activities involving human subjects including those of the WSTR. The WSTR IRB application is reviewed for continuing approval every April. Research staff are located on the WSU Spokane and Everett campuses, as well as the University of Washington campus.

Staff

Glen Duncan

Director

Shelby Tarutis
Research Study Coordinator

Elizabeth Blue

Assistant Director

Siny Tsang Staff Scientist **Ally Avery**

Scientific Operations Manager

Demographics

As of June 30, 2021, the Registry has 9,835 twin pairs (19,670 individuals). Twin pairs live throughout the US and in 43 countries around the world, however, 75% of the Registry lives in the Pacific Northwest.

Current Age Group (%)

9 and younger: 4.1

10-19: 2.5

20-29: 7.8

30-39: 27.8

40-49: 17.0

50-59: 13.5

60-69: 13.5

70 and older: 13.8

Zygosity/Sex (%)

MZ male: 19.1

MZ female: 34.9

DZ male: 8.9

DZ female: 15.7

DZ male/female: 21.4

Ethnicity (%)

Hispanic/Latino: 4.2

Race (%)

White: 89.6

Black or African American: 1.9

American Indian or Alaska Native: 0.6

Asian: 26

Native Hawaiian or Pacific Islander: 0.4

Some other race: 1.5

Two or more races: 3.3





Active Studies

7 studies collected data from twins during FY21.

Study of Environmental Exposure in Twins PI: Glen Duncan (WSU) and Edmund Seto (University of Washington) Funding: NIEHS R33 Award

There is considerable evidence to suggest that exposure to environmental toxins is associated with a variety of adverse health outcomes, such as cardiovascular and lung disease. Most large studies have relied upon measurements made at central monitoring sites to collect data on air pollution, and not within one's personal environment. Current personal environmental monitors are large and cumbersome, or very expensive. This study utilized a new personal monitor (the Personal University of Washington Particle Monitor, or PUWPM, built during the first phase of the project) that measured environmental exposures such as PM2.5. Prior to COVID-19, twins attended an in-person study visit to provide clinical measures including blood pressure, height and weight, waist circumference, and lung function (spirometry), as well as biologic measures such as inflammatory cytokines and cortisol. As a result of COVID-19, we shifted to a 100% remote protocol beginning in January 2021, in which all study procedures were completed at home. Participants

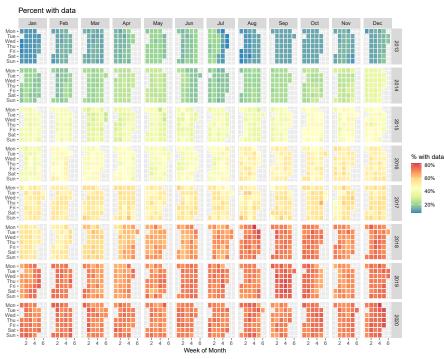


were sent a kit containing all materials and devices needed for data collection. They collected blood pressure using a provided blood pressure device, measured their waist circumference, collected blood using a blood spot card, and collected saliva for salivary cortisol. For both groups, objective data collection was completed at home for two weeks using an activity monitor, a GPS, and the PUWPM. Participants also completed a Food Frequency Questionnaire, a Health and Wellbeing survey, and a neighborhood satisfaction survey. All materials were returned by mail at the conclusion of data collection. 64 pairs completed data collection prior to COVID-19, and 24 pairs completed the remote protocol, for a total of 88 twin pairs.

Google Timeline

PI: Perry Hystad (Oregon State University) and Ofer Amram (WSU) Funding: NIEHS R21 Award

Changes to the built environment are a major contributor to populationlevel health. Most studies examining the relationship between the built environment and health rely on one's residential address, which does not consider how people travel throughout the day. GPS studies have allowed for better estimates of time-activity data, but cost and logistical considerations limit these studies to short time periods that don't provide a true picture of one's activity patterns. Google Timeline (GTL) provides a means of collecting long-term passive time-activity data. GTL data is collected on both Android and Apple smartphones with Google maps installed if location sharing is enabled. Before GTL data can be used in epidemiological research, it needs



to be validated and methods need to be developed to ensure data privacy.

We began contacting twins in October 2020. Potential participants for this study include individuals who participated in the Physical Activity in Twins study or the Environmental Exposures study and carried a GPS and accelerometer for 7-14 days. As of June 30, 44 individuals have shared their GTL data out of 378 invited to participate. Follow-up by phone and email is ongoing. In February 2021, an administrative supplement was funded to collect GTL data from twins who completed the COVID-19 baseline survey. We plan to begin contacting those twins in Fall 2021.

Genetic and environmental influences on the relationships between smoking and cannabis co-use and smoking and alcohol co-use and their association with chronic pain: a twin study. Pl: Crystal Lederhos Smith (WSU) and Sterling McPherson (WSU) Funding: WSU ADARP Award



The objective of this study is to better understand the role of genetics, shared environment, and unique environment on the associations between the co-use of alcohol and tobacco (in the form of cigarette smoking) and cannabis and tobacco (in the form of cigarette smoking) with chronic pain. We hypothesize that there will be significant associations between each form of co-use and chronic pain and that the relationships between both types of co-use and chronic pain will be substantially attenuated after controlling for shared genetic and environmental influences, indicating a substantial role of family factors. This research will prepare us to be at the forefront of more extensive analyses of twin data, including external grant submissions to genotype the registry and examine the relationships between genetic factors and phenotypic expression of substance use and chronic pain. As of June 30, 1,000 twins (500 same-sex twin pairs) have

been invited to participate in the study, and 227 twins have completed the survey. Data collection is ongoing.

COVID-19 Studies

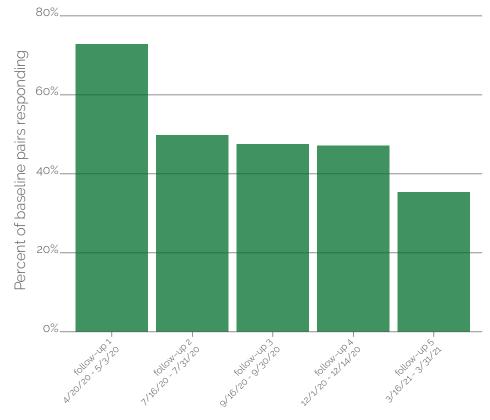
COVID-19 Adult Twin Questionnaire

PI: Glen Duncan

We have collected data with our COVID-19 survey since March 26, 3 days after the initial stay-at-home order was issued in Washington State.

Follow-up response rates are summarized in the graph below. We sent out 4 follow-up surveys during FY21 (follow-up 1 was sent in FY20). The survey in July captured a variety of changes that were taking place in Washington State. After beginning a phased re-opening in early June, a mask mandate was signed into law

COVID-19 Follow-up Survey Pairwise Response Rate



at the end of June, and re-opening was paused until the end of July. The September survey was sent about a week after an historic fire event, where nearly 300,000 acres burned in a single day. The result was thick smoke and unhealthy air throughout the Pacific Northwest. The December survey went out just after the Thanksgiving holiday, when COVID-19 cases were once again on the rise due to travel and holiday gatherings. We sent the one-year anniversary follow-up survey in March 2021, when the vaccine rollout was beginning to ramp up in Washington State. The next follow-up mailing is planned for the fall, and will include new questions about changes that have been made in day-to-day life as well as the workplace as things begin to return to a "new normal." Three manuscripts were published during FY21 using data from the

baseline COVID-19 survey. COVID-19 mitigation strategies such as physical distancing and lockdowns may have unintended consequences on a number of health behaviors and outcomes. The following studies examined changes in behaviors and their impact on stress and anxiety in a sample of 909 same-sex twin pairs.

- Change in physical activity and mental health: The purpose of this study was to examine the association between perceived change in physical activity and mental health. A perceived decrease in physical activity was associated higher stress and anxiety, but relationships were confounded by genetic and shared environmental factors (stress) and age and sex (anxiety).
- Change in alcohol use and mental health: The purpose of this study was to examine if stress and anxiety were associated with changes in alcohol use as a coping mechanism. Twins with higher levels of stress and anxiety were more likely to report an increase or decrease in alcohol consumption in comparison to their cotwin who experienced no change.
- Change in sleep and mental health: The purpose of this study was to examine if changes in sleep amount and quality were associated with anxiety and stress. Stress and anxiety levels were associated with sleep reduction and poor sleep quality.

COVID-19 Parents of Twins Questionnaire PI: Glen Duncan



In FY20, we sent a survey to all enrolled parents of twins to collect data about their experience with COVID-19. The baseline survey was sent on May 7 and ended May 25, 2020, and was completed by 157 parents of twins. A follow-up survey was sent in December 2020, which added new questions regarding changes in childcare, changes in educational attainment, and questions about social support. 66.9% of parents who completed the baseline survey completed the follow-up survey. The next follow-up survey is planned for the fall.

A manuscript examining differences in stress and anxiety among women with and without children was submitted for peer-review in March. Mothers who completed the parents of twins baseline survey were included in this manuscript.

The effect of social restrictions in response to the COVID-19 pandemic on daily activities and fear of crime

PI: Siny Tsang

The purpose of this survey is to examine the impact of the COVID-19 pandemic and corresponding social restrictions in place on the daily life and feelings of WSTR twin pairs. Given the widespread statewide social restrictions put in place, it is possible that people's perceptions and normal interactions within their neighborhoods may have changed. We intend to utilize the survey data to investigate the extent to which safety perception and mood may have changed as a function of the COVID-19 pandemic and the subsequent changes in their social environment. A follow-up survey was sent in May 2021 to assess how much these perceptions changed as society adjusted to a new "normal" routine.

A manuscript was published during FY21 using data from the baseline survey. This study examined the relationships between COVID-19 exposure, fear of COVID-19, and depression among a sample of 732 same-sex adult twin pairs. COVID-19 exposure was related to increased fears of COVID-19 and depression, and depressive feelings increased with fear of COVID-19. The correlation between COVID-19 exposure and depression was partially mediated by fear of COVID-19, however, these associations were confounded by familial influences.

Prospective measurement of daily activities and behaviors: examining temporal changes to risk of COVID-19 in the community among same-sex adult twin pairs PI: Siny Tsang

The purpose of this study is to examine the impact of COVID-19 on the daily activities among a small sample of same-sex twin pairs. In addition to the risk of COVID-19, statewide restrictions (e.g. stay-at-home/ shelter-in-place orders) have resulted in a drastic impact to people's daily lives. Twin pairs enrolled in this study use a daily journal to collect data regarding sleep, activity, diet, and feelings for one week, every few months, for up to two years. The intensive nature of the data collected will allow a close examination of the day-to-day fluctuations in twins' daily activities and provide a more accurate picture of the impact of COVID-19 on individuals' lives. The longitudinal design of the study will further allow us to track these changes over time.



COVID-19 Available Data

Adult Twins

	Baseline	Follow-up	Follow-up	Follow-up	Follow-up 4	Follow-up 5
Dates administered	3/26-4/5 4/20-5/3	4/20-5/3*	7/16-7/31	9/16-9/30	12/1-12/14	3/16-3/31
Survey N (individuals)	4,943	3,066	3,005	2,830	2,811	2,245
Pair N	1,419	760	704	667	663	502
Demographics	X	X	X	X	X	X
COVID-19	X	X	X	X	X	X
Changes in daily activities	X	-	-	-	-	-
Food service utilization	X	X	X	X	X	X
Coping behaviors	X	X	X	X	X	X
Depression	X	X	X	X	X	X
Perceived Stress	X	X	X	X	X	X
Anxiety	X	X	X	X	X	X
Changes in daily life	X	-	X	X	X	X
Employment	-	X	X	X	X	X
Mask adherence	-	-	X	X	X	X
Feelings and emotions	-	X	X	X	X	X
Perception of isolation	-	X	X	X	X	X
Eating behaviors	-	X	X	X	X	X
Physical activity	-	X	X	X	X	X
Sleep	-	X	X	X	X	X
Vaccinations	-	-	-	-	-	X

^{*} only cohort 1

Parents of Twins

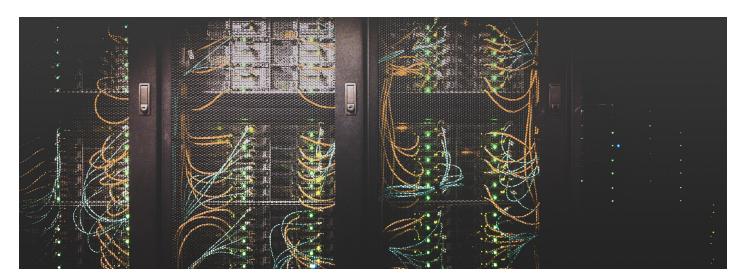
	Parents of Twins Baseline	Parents of Twins Follow-up
Dates administered	5/7-5/25	12/1-12/14
Survey N (parents)	157 parents (p)	105 parents (p)
Twin pair N*	161 pairs (t)	107 pairs (t)
Demographics	×	X
COVID-19	×	X
Food service utilization	×	X
Coping behaviors	X (p)	X (p)
Depression	X (p)	X (p)
Perceived Stress	X (p)	X (p)
Anxiety	X (p)	X (p)
Changes in daily life	X (p)	X (p)
Employment	X (p)	X (p)
Sleep	× (t)	× (t)
Childcare	-	X
Health conditions	-	× (t)
Educational attainment	_	× (t)
Social support		X (p)





^{* 4} parents at baseline and 2 parents at follow-up have 2 sets of twins





Available Data

All pairs enrolled in the Registry complete a baseline survey about health, lifestyle behaviors, and demographics. Follow-up surveys (HWB) have been sent every 2 to 3 years since 2010.

	Enrollment (2008)	Enrollment (2016)	HWB v1 (2010-13)	HWB v2 (2014-2018)	HWB v3 (2019-pres)
Survey N (unique individuals)	12,172	394	9,142	4,658	3,797
Demographics	X	X	X	X	X
Self-report height and weight	X	X	X	X	X
Eating habits	X	X	X	X	X
Physical activity	X	X	X	X	X
Sleeping habits	X	X	X	X	X
Medical history	X	X	X	X	X
Drinking and smoking	X	X	X	X	X
Mental health	X	X	X	X	X
Personality	-	-	X	X	X
Employment	-	X	-	X	X
Military	-	-	-	X	X
Caregiving	-	-	X	X	X
Built environment	X	X	X	X	X

The following peer-reviewed articles were published during FY21, and used data collected in WSTR studies.

- 1. Silventoinen K, Jelenkovic A, Sund R, et al. **Genetic and environmental variation in educational attainment: an individual-based analysis of 28 twin cohorts**. Sci Rep. 2020 Jul 29;10(1):12681.
- 2. Avery AR, Turkheimer E, Tsang S, Duncan GE. Psychometric and Classification **Properties of the Peas in a Pod Questionnaire**. Twin Res Hum Genet. 2020 Aug;23(4):247-255.
- 3. Duncan GE, Avery AR, Seto E, Tsang S. **Perceived change in physical activity levels and mental health during COVID-19: Findings among adult twin pairs**. PLoS One. 2020 Aug 13;15(8):e0237695.
- 4. Olatunji BO, Christian C, Strachan E, Levinson CA. **Central and Peripheral Symptoms in Network Analysis are Differentially Heritable A Twin Study of Anxious Misery**. J Affect Disord. 2020 Sep 1;274:986-994.
- 5. Avery AR, Tsang S, Seto EYW, Duncan GE. **Stress, Anxiety, and Change in Alcohol Use During the COVID-19 Pandemic: Findings Among Adult Twin Pairs**. Front Psychiatry. 2020 Sep 25;11:571084.
- 6. Liechty A, Tsang S, Turkheimer E, Duncan GE. **Association between low back pain and body mass index in adult twins: an analysis of monozygotic and dizygotic twins of the Washington State Twin Registry**. Spine J. 2020 Nov;20(11):1805-1815.
- 7. Tsang S, Avery AR, Duncan GE. **Fear and depression linked to COVID-19 exposure A study of adult twins during the COVID-19 pandemic**. Psychiatry Res. 2021 Feb;296:113699.
- 8. Tsang S, Avery AR, Seto EYW, Duncan GE. Is COVID-19 Keeping us Up at Night? Stress, Anxiety, and Sleep Among Adult Twins. Front Neurosci. 2021 Apr 26;15:665777.
- 9. Afari N, Gasperi M, Dochat C, Wooldridge JS, Herbert MS, Schur EA, Buchwald DS. **Genetic and environmental influences on posttraumatic stress disorder symptoms and disinhibited eating behaviors**. Eat Disord. 2021 May-Jun;29(3):226-244.
- 10. Duncan GE, Hurvitz PM, Moudon AV, Avery AR, Tsang S. **Measurement of neighborhood-based physical activity bouts**. Health Place. 2021 Jul;70:102595.
- 11. Boakye KA, Amram O, Schuna JM Jr, Duncan GE, Hystad P. **GPS-based built environment measures associated with adult physical activity**. 2021 Jul;70:102602.
- 12. Sewaybricker LE, Melhorn SJ, Rosenbaum JL, Askren MK, Tyagi V, Webb MF, De Leon MRB, Grabowski TJ, Schur EA. **Reassessing relationships between appetite and adiposity in people at risk of obesity: A twin study using fMRI**. Physiol Behav. 2021 Oct 1;239:113504.

Manuscript Proposals

We welcome proposals using survey data from the WSTR. Proposals must include an analysis plan as well as information about the individual who will conduct the statistical analysis. If this person does not have previous experience with twin analyses, they will be required to consult with the WSTR behavioral genetics analyst who must ultimately approve the analysis plan. There is an hourly rate involved with this consultation; the hourly rate will be charged after an initial, uncharged one-hour consultation. There is no cost for manuscript proposals that include an individual who can conduct statistical analyses without oversight by the WSTR. More information is available on our website: https://wstwinregistry.org/for-researchers/policies-procedures-for-accessing-the-wstr/

Service Center

Growth and maintenance of the Registry is supported by fees charged to investigators using WSTR twins or data in their research studies.

The following table summarizes estimated and actual spending and sales for the WSTR service center account during FY21.

	Estimated FY21	Actual FY21
Salary & Benefits	\$3,885.80	\$4,396.11
Goods & Services	\$4,360.00	\$7,405.60
Modernization	\$0	\$590.07
Total Spending	\$8,245.80	\$12,391.78
Carryforward from prior year	-\$97.54	\$-332.03
Total Sales	\$8,458.00	\$13,901.68
Balance	\$114.66	\$1,177.87

We continued to use our new simplified monthly service center rate for Registry access in FY21. We had more sales in FY21 than our original estimate. Surplus funds were used to send out a recruitment mailing to a small batch of twins identified by Department of Licensing records. As of June 30, this mailing was still ongoing. The US Postal Service has experienced delays in sending and receiving mail, which has impacted our recruitment mailing response times.

Our remaining balance at the end of FY21 was higher than anticipated due to the recruitment survey mailing costing less than estimated.

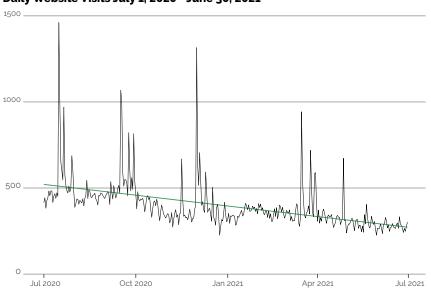
Registry Usage Rates for FY21

The Registry access fee for WSU investigators collecting new data is \$758 per month while twins are being recruited. Should new studies be funded during FY21, rates will be reviewed and adjusted to reflect the increase in use.

The fee for statistical analysis and consultation for manuscript proposals is \$57 per hour.

Online Presence

Daily Website Visits July 1, 2020 - June 30, 2021



During FY21, we had over 151,000 visits to our website, a decrease from FY20 and a continuation of the decreasing trend seen in in FY20. New visitors spent less than one minute on our website and represented 93% of all visits; returning users also spent less than one minute on the website, 88% of referrals to our website are from search engines. Our highest referral source was our survey platform, Qualtrics. We used Qualtrics to send survey invitations for our COVID-19 surveys. After completing a survey, participants were redirected to our website. MedlinePlus, which replaced the NIH Genetics Home Reference website in October, is now the second

highest referral source. The website for the DOL continues to refer a modest number of visitors to the website.

The Registry Facebook page continues to grow organically, primarily through links on our website and by our followers interacting with our page and posts. During FY21, our Facebook page gained 17 new page likes, and as of June 30, 2021, we have a total of 1,405 page likes. Our page reached over 7,000 people during FY21. Changes to Facebook's algorithm have influenced who sees our posts, resulting in a lower reach.

The Registry website is located at www.wstwinregistry.org

The Registry Facebook page is located at www.facebook.com/wstwinregistry

Department of Licensing

Since 1999, we have partnered with the Washington State Department of Licensing (DOL) to identify potential twins who reside in Washington State. Recruitment mailings are sent on a quarterly basis inviting these individuals to join the Registry. The DOL asks all applicants if they are a twin to help prevent identity theft. Before we send recruitment invitations, the list of names we receive from the DOL is thoroughly examined to remove individuals who are already in the Registry, individuals who have requested to be removed from our contact list in the past, and individuals who would not be eligible to enroll in the Registry such as triplets. Twin pairs are identified by matching last name, date of birth, and/or address.

In FY21, we received contact information for 2,361 twins under the age of 18 and 7,424 twins 18 and older, for a total of 9,785 potential twins.



915 N Broadway Everett, WA 98201 1-833-432-8720 www.wstwinregistry.org ws.twinregistry@wsu.edu