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van Dongen, J.

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Appendix 7

Supplement to chapter 9

Based on: van Dongen J., Slagboom PE, Draisma HH, Martin NG, Boomsma DI. The continuing value of twin studies in the omics era. *Nat.Rev.Genet.* 2012; 13:640-653. doi:10.1038/nrg3243

| Supplemental Table 1 Twin registries worldwide | | | | | | | |
|--|--|---|-------|--|--|--|---|
| Country | Twin Registry Name | Registry Characteristics | Age | Website | N twins/ subjects (approx.) ^A | N twins/subjects with DNA available (approx.) ^A | Biospecimens (available for at least subset of the sample) |
| Africa | | | | | | | |
| Guinea-Bissau | Bandim Health Project Twin Registry | Population-based with ongoing longitudinal data collection | 0-30 | www.bandim.org | 2,500 (twins and singleton controls) | 200 twin pairs | Whole blood, plasma |
| Nigeria | Nigerian Twin and Sibling Registry (NTSR) | Cohort of school children + young adult volunteers | 7-24 | - | 1,300 (twins and sibs) | 1,200 (twins and sibs) | Buccal, saliva |
| Asia and Australia | | | | | | | |
| Australia | Australian Twin Registry | Population-based with ongoing longitudinal data collection | 0-90 | www.twins.org.au | 66,000 | 12,000 (twins and other family members) | Serum, plasma, buccal |
| Australia | Western Australian Twin Register (WATR) | Population-based with ongoing longitudinal data collection | 5-30 | in transition | 11,000 (plus other family members) | 600 (twins and other family members) | Whole blood |
| Australia | Queensland Twin Registry | Systematic ascertainment through schools at age 12 and longitudinal follow-up | 12-32 | www.qtwins.org.au | 2,000 twin pairs | 2800 | Blood (including Paxgene tube), saliva; processed to DNA, RNA, serum, plasma, red cells |
| China | Chinese National Twin Registry (CNTR) | Population-based with ongoing longitudinal data collection | All | cntr.bjmu.edu.cn | 35,000 twin pairs | 3,200 | Serum, DNA |
| China | Qingdao Twin Register | Enrollment through medical registration systems, schools, and media publicity | All | - | 8,000 twin pairs | 1,500 twin pairs | Serum |
| Korea | The Healthy Twin Study, Korea | Ongoing in-depth survey based on NKTR | 20-73 | www.twin-korea.org | 783 twin pairs | 3,480 (twins and first degree relatives) | Serum, plasma, buffy coat, urine, stool, cell-line (lymphocytes) |
| Korea | The National Korean Twin Registry (NKTR) | No direct person contact. Zygosity information based on sex only. Basic data in adults on health and disease outcome. | 8-80 | - | 187,130 twin pairs | - | None |
| Korea | South Korean Twin Registry (SKTR) | Volunteer preschoolers, cohort of school children, volunteer young adults | 0-30 | www.ktrc.org | 10,000 twin pairs | 800 twin pairs | Hair, saliva |
| Israel | The Longitudinal Israeli Study of Twins (LIST) | Population-based with ongoing longitudinal data collection | 3-8 | www.teomim.com | 1,500 twin pairs | 1,391 (twins and parents) | Buccal |
| Japan | Keio Twin Registry | Adult and adolescent twins from the general population in the Tokyo area | 14-30 | totcop.keio.ac.jp ; kts.keio.ac.jp ; kotrec.keio.ac.jp | 4,000 twin pairs (plus other family members) | 600 twin pairs | Buccal, blood |
| Japan | Twin Database of the Secondary | 3 cohorts: applicants (11-12 years), students (12-18 years), and graduates | 0-80 | - | 2,200 (plus other family members) | - | None |

| | | | | | | | |
|-----------|--|---|---------|--|------------------------------------|-----------------------------------|---|
| | School Attached to the Faculty of education of the University of Tokyo | (18-72 years). Follow-up of graduates 3 times. | | | | | |
| Japan | Japanese Database of Multiples in Childhood | Main focus of the cohort is on child development | 0-12 | - | 5,000 (plus other family members) | - | None |
| Japan | The Osaka University Aged Twin Registry | Population-based, cohort-study | 50-105 | http://www.twin.med.osaka-u.ac.jp/en/ | 12,000 twin pairs | 280 twin pairs | Whole blood, serum, plasma |
| Sri Lanka | Sri Lankan Twin Registry | Voluntary twin registry component and a population-based database with ongoing data collection | 6-94 | www.ird.lk/Twin%20Registry.php | 35,000 | Plans to collect DNA from 4,000 | Buccal |
| Europe | | | | | | | |
| Belgium | East Flanders Prospective Twin Survey (EFPTS) | Population-based at birth, phenotypic characterization in subsets | 0-47 | www.twin.svzw.com | 8,700 twin pairs, 237 triplet sets | 1,600 (twins and triplets) | Whole blood, saliva, buccal, placental tissue |
| Denmark | The Danish Twin Registry (DTR) | Population-based with ongoing longitudinal data collection | 0-107 | www.sdu.dk/dtr | 170,000 | 20,000 | Serum, plasma, buffy coat, saliva, buccal, urine |
| Finland | Finnish Twin Cohort study | Population-based with ongoing longitudinal data collection | 11-100+ | www.twin.study.helsinki.fi | 87,500 (plus family members) | 14,600 (twins and family members) | Whole blood, serum, plasma, saliva, urine, fat and muscle by biopsy |
| Germany | HealthTwiSt: The Berlin Twin Registry | Registry operated as a CRO. Focus on health, functional genomics and nutraceuticals | 16-80 | www.zwillingsstudie.de | 2,000 twin pairs | 550 twin pairs | Whole blood |
| Germany | CoSMoS (Twin study on Cognitive Ability, Self-Reported Motivation, and School Achievement) | Longitudinal study of voluntarily enrolled twins with 3 measurement occasions. | 7-11 | www.uni-saarland.de/fak5/diff | 808 | - | None |
| Germany | TwinPaW (Twin study on Personality and Well-being) | Cross-sectional study of voluntarily enrolled twins | 15-71 | www.uni-saarland.de/fak5/diff | 608 | - | None |
| Germany | SOEP- twin project | Cross-sectional representative multi-group design, including twins, full sibs, mother-child and grandparent-child pairs. Subset with longitudinal data. | 17-70 | www.uni-saarland.de/fak5/diff | 860 (plus other relatives) | - | None |
| Germany | Chronotyp-twin project (ChronoS) | Cross-sectional study of voluntarily enrolled twins. | 17-70 | www.uni-saarland.de/fak5/diff | 755 | - | None |
| Germany | Bielefeld Longitudinal Study of Adult Twins (BiLSAT) | Voluntary twin sample with longitudinal follow-up 5 times over 15 years | 16-88 | www.uni-bielefeld.de/psychologie/ae/AE04/Forschung/index.html | 2,404 | - | None |
| Germany | Jena Twin Study of Social Attitudes (JeTSSA) | Cross-sectional study of voluntarily registered twins and their parents and spouses | 17-82 | www.uni-bielefeld.de/psychologie/ae/ | 875 | - | None |

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|-------------|---|---|------------|---|------------------------------|--------------------|--|
| | | | | AE04/For schung/index.html | | | |
| Italy | Italian Twin Register | Phenotypic characterization in subsets of the sample and longitudinal data collection in newborns | 0-99 | www.iss.it/gemelli | 25,000 | 2400 | Whole blood, serum, plasma, buffy coat, saliva |
| Netherlands | Netherlands Twin Register (NTR) | Population-based with ongoing longitudinal data collection | 0-100 | http://www.tweelin.genregister.org/en/ | 87,500 (plus family members) | 18,000 | DNA, RNA, cell lines, serum, plasma, buccal, urine |
| Norway | Norwegian Twin Registry (NTR) | Population-based with ongoing longitudinal data collection | 18+ | www.fhi.no/twins | 40,000 | 4,800 | Whole blood, buccal swabs, plasma |
| Spain | Murcia Twin Register (MTR) | Population-based with ongoing longitudinal data collection | 45-71 | http://www.um.es/registros/melos/index.html | 2,281 | 743 (female twins) | Whole blood, saliva (gDNA, plasma & PBMC) |
| Sweden | Swedish Twin Register (STR) | Population-based with ongoing longitudinal data collection | 5-100+ | http://ki.se/ki/jsp/polopoly.jsp;jsessionid=acR0zITHzWEclO_cNC?e_n&d=9610 | 194,000 | 44,600 | Whole blood, serum, saliva |
| UK | TwinsUK registry | Population-based with ongoing longitudinal data collection | 18-90 | www.twin.suk.ac.uk | 12,000 | 7,000 | Whole blood, serum, plasma, buffy coat, saliva, buccal, urine, skin, fat, muscle |
| UK | The Cardiff Study of All Wales and North West of England Twins (CaStANET) | Population-based | | http://medicine.cf.ac.uk/psychological-medicine-neuroscience/areas-research/child-and-adolescent-psychiatry/castanet-twin-register/ | 6000 twin families | 300 twin pairs | None |
| UK | Twins Early Development Study (TEDS) | Population-based | | http://www.teds.ac.uk/ | 10,000 twin pairs | 10,000 | None |
| UK | The Twins and Multiple Births Association Heritability Study (TAMBAHS) | Volunteer-based cohort of twins - closed to participation | 0-5 | www.birmingham.ac.uk/research/activities/mds/projects/HAPS/PHEB/UROGENEPID/projects/TAMBAHS.aspx | 1,600 (plus parents) | - | None |
| UK | Birmingham Registry for Twin and Heritability | Population-based cohort with ongoing follow-up | prenatal-4 | www.birmingham.ac.uk/research/activi | 250 (including mothers) | 50 | Cord blood, saliva |

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|---------------|--|---|-----------------------|--|--|-----------------------------------|--|
| | Studies (BIRTHS) | | | ty/mds/projects/HAPS/PHEB/UROGENEPID/projects/BIRTHS | | | |
| North America | | | | | | | |
| Canada | University of British Columbia Twin Project | National cross-section sample of general adult population | 18-93 | - | 2,000 twin pairs | - | None |
| USA | California Twin Program | Population-based native residents | cohort born 1908-1982 | twins.usc.edu | 115,000 located, 37,000 twin pairs with complete phenotypic characterization | 3,4000 | Extracted DNA, frozen white cells, serum, plasma salivary DNA, DNA from buccal scrapings |
| USA | Colorado Twin Registry | Population-based with ongoing longitudinal data collection | 1-41 | ibg.colorado.edu/research/ctr.html | 14,000 (plus family members) | 5,500 (twins and family members) | Extracted saliva-derived DNA |
| USA | Florida State Twin Registry (FSTR) | Twins and other multiples enrolled in Florida schools (grades K-5) | 5-13 | www.psy.fsu.edu/~taylorlab/TwinRSch.htm | 2,591 twin pairs (and other multiples) | - | None |
| USA | Georgia Carolina Cardiovascular Twin Study | Longitudinal study, mixed sample of American twins of various ancestries recruited at public middle and high schools. | | - | 1,664 | 1,607 | |
| USA | International Twin Study | Continent-wide volunteers with chronic disease | All ages | twins.usc.edu | 17,000 twin pairs | 1,000 | Extracted DNA, Frozen white cells, salivary DNA, serum, stool |
| USA | Michigan State University Twin Registry | Population-based and high-risk samples, some of which are longitudinal | 3-30 | www.msutwinstudies.com | 20,000 (plus family) | 4,100 (plus family) | Saliva, buccal, blood spots |
| USA | Mid-Atlantic Twin Registry (MATR) | Population-based, ascertained at birth | 0-94 | www.matr.vcu.edu | 56,000 | 1,500 | Whole blood, serum, plasma, buffy coat, saliva, buccal |
| USA | Minnesota Twin Family Study | Ongoing population - based longitudinal study | 11-47 | mctfr.psy.h.umn.edu | 5,000 (plus family) | 10,000 (twins and family members) | Blood-derived or saliva-derived DNA |
| USA | Minnesota Twin Registry | Cross-sectional sample of twins born between 1936 and 1964. Subsamples followed up through surveys | 28-56 | www.mntwin.umn.edu | 15,000 (plus family) | - | None |
| USA | Missouri Family Registry | Vital record ascertained | 1.5-44 | - | 25,979 | 2,575 | Blood, saliva, fecal |
| USA | NAS-NRC (National Academy of Sciences-National Research Council) Twin Registry of World War II Male Veterans | Male twins born between 1917-27, both of whom served in the military, mostly during World War II | 85-95 | iom.edu/Activities/Veterans/TwinsStudy.aspx | 31,848 | 700+ | Blood and other materials collected for various investigations |
| USA | NAS-NRC (National | Longitudinal data collection from 1990 – | 85-95 | aging-memory.d | 13,000 | 770 | Post-mortem brain tissue, DNA |

| | | | | | | | |
|---------------|---|---|-------|--|--|------------------------------|---|
| | Academy of Sciences-National Research Council) Twin Registry of World War II Male Veterans – Duke Twins Study Component | 2006, primary aims to investigate cognitive decline and dementia in later life. | | uhs.duke.edu/twins.html | | | from buccal or blood |
| USA | Pittsburgh Registry of Infant Multiplets (PRIM) | Population-based database of twins ascertained at birth – currently no follow-up data | - | www.pitt.edu/~mmv/prim/prim.htm | 2,956 | - | None |
| USA | University of Washington Twin Registry | Population-based with ongoing longitudinal data collection | 18-97 | depts.washington.edu/uwccer/ | 6,688 twin pairs | 8,7000 | Whole blood, saliva, serum, plasma, urine, buccal |
| USA | Vietnam Era Twin Registry (VET Registry) | Closed cohort of male twins whom served in the military during the Vietnam conflict (1964-1975) | 54-72 | www.seattle.eric.research.va.gov/VETR/Home.asp | 14,760 (plus offspring and spouses of twins) | 1,685 | Whole blood, serum, plasma |
| USA | Wisconsin Twin Panel (WTP) | Population based, longitudinal data, extensive phenotypic characterization, follow up of selected samples | 0-23 | www.waisman.wisc.edu/twinresearch | 19,638 twins (plus parents and sibs) | 3,489 (twins, parents, sibs) | Saliva, buccal |
| South America | | | | | | | |
| Chile | The University of Chile School-Age Children Twin Registry (REMEUCHI) | Cohort of school children graduated from high school | 18 | - | 327 twin pairs | - | None |
| Cuba | Cuban Twin Registry | Population-based with ongoing longitudinal data collection | All | - | 55.400 twin pairs | 250 twin pairs | Blood-derived DNA |

