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# The Western Australian Twin Register: A Population-Based Register of Adult and Child Multiples

Jessica D. Y. Lee and Lyle J. Palmer

Laboratory for Genetic Epidemiology, Western Australian Institute for Medical Research, Perth, Western Australia, Australia,  
and UWA Centre for Medical Research, University of Western Australia, Perth, Western Australia, Australia

The Western Australian Twin Register (WATR) was established in 1997 to study the health of all child multiples born in Western Australia (WA). The Register has until recently consisted of all multiples born in WA between 1980 and 1997. Using unique record linkage capacities available through the WA data linkage system, we have subsequently been able to identify all multiple births born in WA since 1974. New affiliations with the Australian Twin Registry and the WA Institute for Medical Research are further enabled by the use of the WA Genetic Epidemiology Resource — a high-end bioinformatics infrastructure that allows efficient management of health datasets and facilitates collaborative research capabilities. In addition to this infrastructure, funding provided by these institutions has allowed the extension of the WATR to include a greater number of WA multiples, including those born between 1974 and 1979, and from 1998 onwards. These resources are in the process of being enabled for national and international access.

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The Western Australian Twin Register (WATR), established in 1997 by the Telethon Institute of Child Health Research (TICHR), comprises all multiple births (twins, triplets, quadruplets and quintuplets) born in Western Australia (WA) between 1980 and 1997. As previously described by Hansen et al. (2004), the purpose of the Register was primarily to enable the WA Twin Child Health (WATCH) Study, which looked at the role of genetic and environmental factors which contribute to the development of asthma and allergies. Initially, all multiples born in WA from 1980 to 1992 were invited to participate in the study. This was later extended to include 1993 to 1995 and 1996 to 1997 births.

We have since built upon the initial child database to develop the WATR into a larger resource, by registering as many multiples born in WA as can be identified by probabilistic record linkage techniques available through the WA Data Linkage System (WADLS). The WATR will contain all consenting multiples born in WA between 1974 and 2004, and will

continue to enroll new birth year cohorts of multiple births indefinitely. This will produce the only Australian population-based register of multiples who have consented and are willing to participate in future research studies. Through new collaborations with the WA Genetic Epidemiology Resource (WAGER; <http://www.wager.org.au>) and the Australian Twin Registry (ATR; <http://www.twins.org.au>), additional funding and infrastructure has been provided to drive this initiative and to enable the WATR for national and international access.

This article will provide an update on the status and activities of the WATR. The use of the WADLS to identify WA multiples and the storage of multiple demographic data in WAGER will be described, and how they have been used in the extension of the Register to include multiples born from 1974 onwards. As the registration of multiples for the WATR is ongoing, the figures used in this paper are current as of July 2006.

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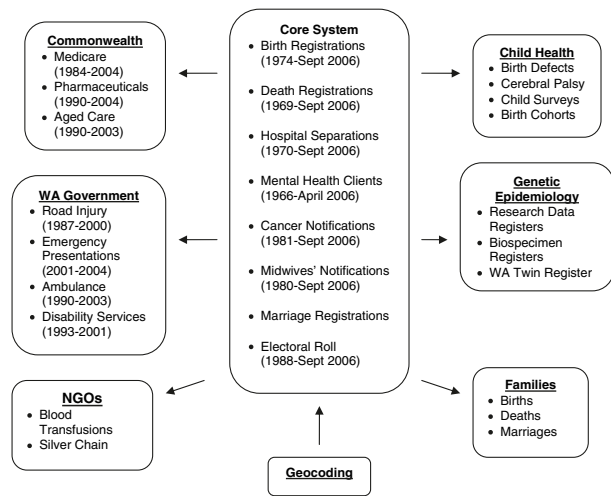
## Identification of WA-Born Multiples With the WA Data Linkage System

The population of WA is approximately 2 million, with approximately 1.4 million people living in and around Perth, the capital city. It is a cosmopolitan city, with wide ethnic and cultural diversity. WA has a large number of unique population-based datasets that are ideal for genetic epidemiological research. The WADLS, established in 1995, comprises over 3 decades of health data on the entire WA population. The core WADLS data are based on linkage within and between the WA statutory collections (all births, deaths, hospitalizations, midwives' records, mental health and cancer registrations), Commonwealth data such as the

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Address for correspondence: Jessica Lee, Western Australian Institute for Medical Research, Centre for Medical Research, University of Western Australia, QE-II Medical Centre, B Block, Hospital Avenue, Nedlands, WA, 6009, Australia. E-mail: [jdlee@cyllene.uwa.edu.au](mailto:jdlee@cyllene.uwa.edu.au)



**Figure 1**

WA Data Linkage System: Current as of September 2006.

PBS and MBS registers, and additional internationally unique population-based disease registries and health surveys (Figure 1; Croft et al., 2002; Holman et al., 1999). A number of population-based disease registries are linked to the core datasets, for example, mental health, type-1 diabetes, cerebral palsy, birth defects, and cancer (Croft et al., 2002; Hansen et al., 2002; Holman et al., 1999; Stanley & Watson, 1985). Linkages are created and maintained through rigorous privacy protocols, probabilistic matching and extensive clerical review. This unrivalled resource enables the study of total population longitudinal data and family record linkage in an unbiased way. Stage 1 of the Family Connections project has recently linked families within the core WA total-population-based databases back to the early 1970s using electronic registrations. The potential to link the core population-based datasets to twin cohort and family studies means that we have the ability to investigate the changing roles of genes, environment, gene-gene, and gene-environment interactions over the entire lifespan in population-based samples of twins. No other state in Australia, and very few countries internationally, have this capacity.

In WA, records of women who have given birth in the state are held as a legal requirement by the Registry of Births, Deaths and Marriages. This information was released to the WATR by the Registrar General of WA after it was agreed that the use of the data would be of benefit to the community. As electronic health data currently in WA dates back to 1974, we were able to identify all subsequent multiple births in WA through maternal health data. These were linked with WA mortality data to identify which multiples had died, and siblings of these people were deemed ineligible for WATR recruitment to avoid unnecessary distress to families. All remaining names were then linked with the WA electoral roll to source addresses to contact eligible multiples. Using WADLS,

we can identify eligible WA multiples and add data from 1974 to 1979, 1998 to 2004, and from 2005 onwards as the data become available.

### Integration of Western Australian Twin Register Datasets Through the Western Australia Genetic Epidemiology Resource

WAGER, funded by an Enabling Grant from the National Health and Medical Research Council of Australia, is a state-wide medical informatics project that is currently enabling the integration of all extant disease-specific clinical, epidemiological and genetics resources available in WA with each other and with the core WADLS data. The WAGER project is developing a national resource that will build on the unique population health data collected by WADLS, and will result in one of the largest and best characterized population-based enabling facilities for epidemiological and genetic epidemiological research in the world. The project is led by the Laboratory for Genetic Epidemiology at the WA Institute for Medical Research (WAIMR). An informatics hub, including five programming staff, has been constructed at WAIMR as part of the WAGER project. The WAGER team is in the process of assisting every medical research team with relevant data in WA to upgrade their data management systems to a high-end relational database. As part of this initiative, WAGER is also upgrading the informatics infrastructure (i.e., laboratory information management system) for all research groups who curate biospecimen banks in WA. These resources are also enabling high-end and secure informatics support for the WATR.

Currently, all the demographic data from multiples born in WA from 1980 to 1997 are stored at TICHM and the WATR act as custodians. These data were derived principally from Department of Health Midwives' data in combination with Birth Registrations. As the recruitment of adult multiples born from 1974 to 1979 has proceeded in 2006, demographic data obtained regarding these adult multiples is being collected and managed by WAGER. Both the new adult and extant child data are in the process of being consolidated and centrally stored in the core WAGER informatics facility at WAIMR.

The rationale for this consolidation is to make the management and security of WATR data consistent across both sets of multiples (those born 1980–1997 and 1974–1979). The WAGER infrastructure will facilitate data access and linkage for external collaborators who may wish to use the WATR resource for research studies. By storing the data as part of WAGER, we will be able to regulate and standardize access to both sets of WATR data in one location. We are in the process of developing a formal relationship with the Australian Twin Registry (ATR), a nationally funded resource for medical and scientific research (Hopper et al., 2006). Therefore, the ability to effectively manage all WATR data for future correspondence with registered multiples is imperative. The WATR is further

**Table 1**

Number of Multiples Born 1974 to 1979 Eligible for Contact for Adult Expansion of the WATR

Multiple group	No. multiples per group	No. multiple groups	Total
Twin pairs	2	566	1132
Incomplete twin pairs	1	250	250
Triplet sets	3	7	21
Incomplete triplet sets	2	2	4
Total			1407

underpinned by other recently developed core resources such as the WA DNA Bank, which provides large scale, best practice and cost-effective banking of DNA and sera/plasma in WA.

**Current Status of the WATR (1980 to 1997 Cohort)**

The current WATCH study comprises all multiples born in WA from 1980 to 1997 inclusive, and has a sample size of approximately 5400 participants. However, now with data from the Registrar General’s office, and the resources such as WADLS and WAGER as described above, we are able to expand the WATR to include data from 1974 to 1979, 1998 to 2004, and from 2005 onwards. The data given to us from participants of the 1980 to 1997 cohort has allowed us to look at the health of multiples and their families, particularly asthma and allergies. The extended register will enable the continued study of these conditions, as well as many other aspects of health and behavior.

**Expansion of the WATR (1974 to 1979 Cohort)**

The purpose of expanding the WATR is to create a population-based register of multiple births in WA willing to participate in research studies. TICHR currently manages WATR registered child multiples born 1980 to 1997, and will manage the 1998 onwards births expansion, expected to commence late 2006. The recruitment of multiples born between 1974 and 1979 (referred to as ‘adult multiples’) commenced in January 2006 by WAIMR.

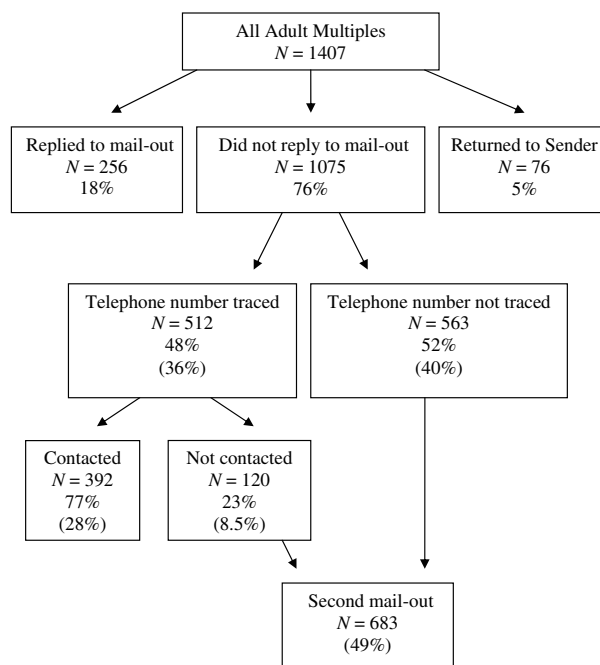
**Recruitment of Adult Multiples (1974 to 1979 Cohort)**

The recruitment of adult multiples began with a mail-out to all identified eligible multiples. This mail-out consisted of an invitation letter to join the Register, an information leaflet, consent form, registration form, reply-paid envelope and an ATR newsletter. The registration form asked for demographic and basic twin family details (e.g., zygosity and presence of other twins in the family). The ATR newsletter was included with the aim of showing potential multiples examples of current Australian twin research. By registering, multiples were consenting to be contacted at a later date by researchers who may request their participation in future research studies. Participation to the WATR is entirely voluntarily,

and multiples were informed that should they register to be part of the WATR, they were under no obligation to participate in any future studies. All registrations were confirmed by letter or telephone call.

Follow-up calls were carried out for all eligible multiples from whom we had not received a reply following the initial mail-out. Their contact phone numbers were sourced through the White Pages, and telephone calls were conducted between 6 and 8pm on week nights. When contact was made in this manner, multiples were reminded to send their consent and registration forms. If they no longer had them, they were given the option to register over the phone or have an invitation package resent to them. They were also directed to the WATR website where consent and registration forms could be downloaded. For potential participants who could still not be contacted, invitation packs were re-sent.

A total of 1407 adult multiples were identified from birth records as being eligible for contact for the 1974 to 1979 extension of the WATR. Only twin and triplet sets could be sourced, with no quadruplets or quintuplets being born in WA during these years. For 250 sets of twins, contact details of only one twin could be sourced. Similarly, contact addresses for all three triplets could only be sourced for seven of the nine triplet sets — only two of the three triplets could be found for these sets (Table 1). This was due to the inability to source their addresses through the WA electoral roll. In such cases, the invitation letter was



**Figure 2**  
Recruitment procedure for adult multiples (1974 to 1979) for the Western Australian Twin Register.

Note: The percentages without brackets are a percentage of the level above; the percentages with brackets are a percentage of the total number of multiples eligible (n = 1407).

**Table 2**

Results of the Follow-Up Phone Calls to Multiples Born in 1974-1979 Who did not Respond to Initial Invitation

Results of phone call (after all attempts made)	Number	%
Registered over the phone	151	29
Not interested	133	26
Asked to re-send forms	89	17
Would send back forms	11	2
Preferred to be contacted later	8	2
Away	20	4
Left message	40	8
No answer	60	12
Total	512	100

altered, requesting the contactable twin/triplet to invite their sibling to join the WATR on our behalf.

As of July 2006, 485 adult multiples have registered, of which there are 130 complete twin pairs, and two complete triplet sets — an overall response rate of 34%.

Following a low response rate from the initial mail-out ( $n = 256$ , 18%), we contacted potential participants by telephone after sourcing their telephone numbers from the White Pages. Seventy-six (5%) invitation packs were returned to sender, therefore their addresses were no longer current and therefore could not be used to source telephone numbers. However of the 1075 remaining multiples, only 512 telephone numbers could be sourced (Figure 2).

Of the 512 multiples to be contacted by telephone, contact was made with 392 multiples. Most were registered over the phone ( $n = 151$ ), 89 requested forms to be resent, 11 said they would send the forms back and eight preferred to be contacted at another time. One hundred and thirty-three multiples indicated that they were not interested. The remaining 120 were not personally contacted — messages were either left with a household member or answering machine, we were informed that they were away, or there was no answer. Three attempts were made where there was no answer (Table 2).

A second mail-out was performed to people from whom we had not heard back from following the initial mail-out, and could not contact via telephone ( $n = 683$ , 49%).

## Discussion

Using record-linkage mechanisms, it is possible to identify multiple births to establish a population-based register in WA (Croft et al., 2002). However, our experiences in recruiting 1974 to 1979 born adult multiples have proved to be more challenging than expected, especially considering that we are asking for registration of multiples, and not actual consent or participation for a particular research study. Our response rate (34%) has been low compared to the

1980 to 1992 (48%), 1993 to 1995 (60%), and 1996 to 1997 (65%) cohorts (Hansen et al., 2004). However it is possible that because multiples were not being asked to participate in a specific study, but merely registration and consent to be contacted for future studies, it was not enough to be of interest to this older cohort. Additionally, with the younger childhood cohorts, parental consent was required, and not consent of the actual multiple — parental influence may have been a factor as parents may have greater willingness to participate in research for the benefit their children. The sense of belonging to a twin register, and the pride of raising a multiple birth family, is likely to also have influence on families of multiples and their willingness to participate. This was noted with a significant number of parents of adult multiples who received the invitation packages (due to multiples moving out of home) who forwarded them onto their progeny at their new address. Several parents contacted us to confirm that their children had indeed registered, and numerous adult multiples also commented that their parents had continuously 'nagged them' to ensure they had registered for the WATR.

Future recruitment of adult multiples will include a general call for volunteers through a targeted media campaign. In addition, there are plans to digitize paper records currently held by the Registrar General's Office back in time (initially to 1950); this will allow further recruitment of adult multiples.

The WATR website, <http://www.watr.org.au>, aims to provide easily accessible information for potential WATR multiples. Online registration will be enabled on the website in late 2006 — which will offer an alternative, and potentially more convenient, method for registering multiples.

## Limitations

Through this experience, we have identified that the use of the WA electoral roll and the White Pages have a number of limitations, most of which relate to the mobility of the target age group. The WA electoral roll covers approximately 86% of the WA population (Hansen et al., 2004), and at the time of linkage, was current to January 2005 (Data Linkage Unit, 2006). Given that we could only source addresses from the electoral roll following linkage of the Registrar General's data, the only other option to contact multiples who had not responded to the initial mail-out was to search the White Pages for telephone numbers. However we could only source telephone numbers for 512 multiples of the 1075 we needed to contact by this means. For the 252 identified yet uncontactable multiples (250 incomplete twin sets, two incomplete triplet sets), we had no option but to rely on sibling encouragement and word of mouth to recruit the remaining multiples.

As the multiples we were contacting were between 27 and 32 years of age, many have moved out of home and have therefore changed address, making both the electoral roll and White Pages inadequate.

On the other hand, many are still living at home with their parents, and are therefore not listed under their own name in the White Pages. Many women have also married and changed surnames and are not registered in the White Pages under their new name.

The White Pages lists mostly home phone numbers, and only occasionally mobile phone numbers. This is problematic, as people in our targeted cohort are of working age, and are mostly at work during the day. Although we conducted telephone calls between 6 pm and 8 pm, a significant number were not home during these hours. We were also wary that many people do not like being contacted during dinner time. In cases where this issue was raised, we asked for an alternative time they would prefer to be contacted, and this was followed up accordingly.

Our experiences in trying to recruit adult multiples have highlighted the limitations of our methods, and will be taken into consideration when moving into the next phase of registration of multiple births born from 1998 to 2004. The low response rate from this stage of recruitment may only be an effect of the targeted age group (27- to 32-year-olds), and it is hoped that the registration of multiples born 1998 and onwards will be more successful. The incorporation of the demographic data from the WATR into an informatics resource as extensive WAGER will facilitate future research, and allow easier collaboration with external researchers. By continually updating the WATR, we aim to provide an important resource which will be used as a basis for future research in Australia.

The population-based sampling of multiples allowed by the WATR minimizes the possibility of bias seen with volunteer registers, where twins included are more likely to be similar than twins not.

### Governance and Administration

The WATR is a joint project of the TICHR and the WAIMR, and is a node of the ATR (Hopper et al., 2006). A WATR management committee was set up to regulate and oversee the activities of the WATR. The committee includes an Ethics Committee member and representatives from the Australian Multiple Births Association (WA Branch) and the Perth and Districts Multiple Births Association (Inc). All future research studies proposing to use the WATR will be reviewed and approved by this Committee.

### Access to the WATR by researchers

The WATR welcomes approaches by all local, national and international researchers. An access policy, which will be overseen by the WATR Management Committee, is currently being established to define the guidelines and procedures required by researchers to use WATR data. This policy will ensure that researchers have fair and equitable access to the data, and that proposed research studies are consistent with the overall program of twin research activities. It will

also ensure that all proposed studies have obtained approval from relevant institutional ethics committees, and the Confidentiality of Health Information Committee (CHIC) — a committee who must approve all projects requiring the use or disclosure of personal health information from the WA Department of Health. As multiples who register for the WATR give their consent to be contacted by the WATR for future twin studies, all initial correspondence to WATR-registered multiples will be conducted by the WATR. After consent is received from the multiple, contact details will be passed to the research group who may then contact them directly.

### Conclusions

WATR will continue to enroll new birth year cohorts backwards in time from 1974 and forwards in time from 1998 indefinitely. This will produce the only population-based register of Australian multiples willing to participate in research studies.

### Acknowledgments

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