



Acta Genet Med Gemellol 39:71-84 (1990)  
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Sixth International Congress  
on Twin Studies

## **Twin Children in Volunteer Registries: Biases in Parental Participation and Reporting**

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**Abstract.** The biases in voluntary participation by adult twins are well known but less attention has been paid to twin children where parents decide on participation and provide much of the information. Several aspects of reporting including the assessment of zygosity are compared in four large Australian data bases: 1) a nationwide compulsory (and hence representative) survey of literacy and numeracy; 2) a nationwide "Twins in School" survey of parents and teachers of twins run through Education Departments and AMBA, the parents organisation in conjunction with LaTrobe; 3) the LaTrobe Twin Study which is a longitudinal program involving frequent interactions between families and researchers, and 4) the Australian NHMRC Twin Registry which has surveyed a large sample of their families with twin children by mail. One potential bias comes when recruitment is on a continuing basis as in the LaTrobe Twin Study and the Australian Twin Registry when differences between "early" and "late" enrolling families arise. One difference between the four samples arose from parents being much more likely to contrast their twins and to report problems in one but not the other, whereas teachers' and psychologists' assessments of these same children generally reported much smaller intrapair differences. Future studies should have some common questions to provide comparative data on such biases. Key questions are proposed for this area, mainly on the perceived need for different forms of remediation, together with other recommendations about the minimal essential baseline data set for a registry.

**Key words:** Twin registers, Schooling, Families of twins, Zygosity assessment, Parental bias

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Twin registries play a vital role in providing data sets large enough for comprehensive biometrical genetic analysis [15] and where sufficiently many people are

sampled that the genetic analysis of even rare conditions can become feasible [23]. But in such large samples, small biases in recruitment and/or response can have significant effects on the outcome of genetic analysis – witness the apparent disparity between London and Birmingham in the heritability of regularity of menstrual cycles [1]. Such biases can be well defined in the various registries based upon veterans [5,7] and some correction can be made in genetic analysis for truncated sampling [18] and for differential enrolment [16].

But situations arise such as twin-family designs [14] where it is not the twins who are being enrolled or are reporting, and this can introduce a very different set of biases. An obvious example is that of twin children who do not volunteer but who are volunteered by their parents. In some ways, the fact that the parent is often reporting on both twins is useful in eliminating those biases concerned with differential enrolment or response [16]. On the other hand a whole new set of influences can emerge from the way in which parents can contrast and compare their twins, possibly exaggerating intrapair differences [11]. This would be the most likely explanation for the frequent reporting of significantly negative DZ correlations on parental assessment of temperament. Thus, in reports from 576 volunteer families from the UK Institute of Psychiatry Registry and from the UK parents organization TAMBA [21], the MZ correlation, averaged over all ages and measures of temperament, was +0.23, while the DZ one ranged from +0.32 to –0.42 and averaged –0.13. Such negative correlations are less often found where temperament measures are derived from other sources than parental report [11].

This paper is an examination of four large data sets on Australian twin children, exploring three issues: the assessment and consistency of measures of zygosity, the adequacy of reports of school performance and the nature of a basic data set. Ever since the first discussions on twin registries [27], there have been suggestions for pooling data, the first requirement for which must be common and consistent baseline information so that potential differences and biases between the samples can be identified.

## THE SAMPLES

The four samples are outlined in Table 1. While only one (no. 4) is formally a twin registry, each has specific and unique features of a large twin data set and all have some data on school performance, but in very different forms and of very differing quality. Over the last 12 years the LaTrobe Twin Study (LTS) has been studying the behavioural and biological development of over 2000 children. Keeping families involved over this period and minimising attrition [8] has meant the provision of many services. Thus, the LTS families constitute a well-informed, motivated group on whom there are extensive psychometric data on abilities and especially on reading [9] to complement equally extensive parent and teacher reports.

“Twins in School” was a nationwide project run by LaTrobe in conjunction with the parents’ organisation, AMBA. No two Australian state education systems participated in the same way, either in terms of sampling or of administration of

the questionnaires [6]. What makes this survey relevant, apart from the number of twins, is that it was designed partly to compare parental and teacher reports on such issues as zygosity, interaction between the twins, school performance and the need for remediation.

**Table 1 - Details of the four data sets**

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1. **LaTrobe Twin Study (LTS):** 2260 children, comprising 698 sets of twins, 692 siblings, 122 cousins and 14 surviving cotwins studied over 12 years with individually administered psychometric tests.
  2. **"Twins in School":** A national questionnaire survey in 1986-87 with 784 replies from parents and 1264 replies from the teachers of their primary school age twins.
  3. **The Australian Council for Educational Research 1975 Australian Study in School Performance (ASSP):** A representative sample of 6628 10-year-olds (including 168 twins) and 6247 14-year-olds (including 129 twins) with group ability tests and teacher questionnaires.
  4. **Australian NHMRC Twin Registry (ATR):** With 6879 volunteer families with twins below age 16 - data here based on the first 1205 replies to the baseline questionnaire.
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The Australian Study in School Performance (ASSP) was also a nationwide study, but under the aegis of the federal government, and involved a totally representative sample of children aged 10 and 14 in normal schools in 1975. One in 43 of these children were twins, but there is no way of identifying zygosity or even determining if only one or both members of a twin pair were tested. Apart from its representativeness, which has been fundamental in comparing with the more selective LTS sample [9], the extensive group testing of literacy and numeracy, together with teacher reports, has facilitated comparisons of twins and singletons, particularly in the area of the nature of reading problems [10]. There are very well constructed criteria for defining who has or has not acquired mastery of literacy and numeracy.

The Australian National Health and Medical Research Council Twin Registry (ATR) began from initiatives in the late 1970s and now involves over 16,000 twin pairs who have expressed a willingness to participate in research. The ATR does not carry out its own research, so much as facilitates contact between researchers and interested twins. This does mean that when twins enrol (or in the case of younger twins, are enrolled by their parents) they are not volunteering for any specific research project. Particularly in the case of the child twins, recruitment has been on an *ad hoc* basis, from maternity hospitals, the parents organisation (AMBA), infant welfare centres, schools etc, as well as responses to media coverage of the ATR. It is thus a good example of the diversity and limitations of a large volunteer sample. While much work has been done with the adults in the ATR [eg, 15], there was little emphasis on the younger twins until a baseline questionnaire began to be distributed by mail in 1986. This questionnaire focusses on the birth, zygosity and common childhood illnesses and behaviour problems and is designed less to collect research data than to help identify specific children for future research.

## ZYGOSITY ASSESSMENT

The first step in developing a registry is some accurate measure of zygosity. However, the well-proven methods of questionnaire assessment of zygosity developed with adolescents and adults [20] may not apply so much to younger children where factors such as the twin transfusion syndrome can lead to MZ pairs being less similar than DZ ones [3]. Furthermore, unlike hospital-based registries [24] there is not the availability of records and of tissue to determine zygosity more explicitly. Table 2 indicates the extent of discrepancy on the two most common questions. While 79% are consistent and can fairly reliably be assigned to MZ or DZ pairs, the question is what to do with those where some discrepancy exists.

**Table 2 - Parental replies to main zygosity questions in the Australian Twin Registry<sup>a</sup>**

Which best describes your twins?			
	As alike as two peas in a pod	Of ordinary family likeness	Missing
I believe the twins to be			
Identical	44.1	8.1	0.4
Non-identical	4.1	34.9	0.9
Not sure	5.1	3.7	1.8

<sup>a</sup> Data are percentages of N = 898 replies. A further 307 replies were not completed or were from opposite-sex DZ pairs.

One view would be to say that mothers can usually distinguish some differences between even the most identical twins and that the question on identical/non-identical should take precedence over the one about similarity. On the other hand, through the national zygosity testing service run by Dr. R.J. Mitchell at LaTrobe, it has become apparent that there continues to be a significant number of families confused about zygosity, mainly by medical and paramedical staff who perpetuate the myth that "one placenta = MZ, two = DZ", or who do not explain the physical discrepancies common in MZ twins with the transfusion syndrome [25]. In this case it is the identical/non-identical question which is more suspect. The issue is complicated further by recent changes in the nature of the twins being conceived [4], which makes any application of Weinberg's rule suspect when applied to children born over this period of change. A further complication comes from the fact that this is a sample volunteered by their parents not themselves and that the usual biases in twin enrolment [17] may give little guide as to the MZ/DZ ratios to expect.

Table 3 lists many of the questions often asked about physical features and the extent to which twins are mistaken. There is a particular logistic problem in the ATR in that parents of opposite-sex twins are directed to miss the entire zygosity section. While this is efficient in terms of questionnaire completion, data are coded

in a way which makes it difficult to differentiate their twins from same-sex twins whose parents have failed to answer the questions: hence the variability in the first column of Table 3. Correcting this simple oversight is a major task in such a large sample. This Table has generally useful information on the typical patterns of response, but the key statistic is the last column which is the ratio of MZ/DZ twins perceived as being very similar and constitutes a crude index of discriminability. Thus, the best of the physical features is facial appearance and more reliance can be placed on twins mistaken by the father than by the mother, who is often acutely aware of minute differences.

**Table 3 - Australian Twin Registry responses to other zygosity-related questions (N = 1205)**

<b>(a) To what extent are the twins alike:</b>				
	Missing data (or opposite sex)	Not at all	Somewhat	Very much
Height	24.6	12.0	35.7	27.8 (3.53)
Weight	25.0	13.6	40.2	21.2 (4.44)
Facial appearance	25.5	15.8	34.0	24.7 (19.17)
Hair colour	24.2	11.5	14.8	49.5 (4.97)
Eye colour	24.6	9.2	9.5	56.7 (4.49)
Shape of earlobe	29.5	8.6	18.7	43.2 (2.62)
<b>(b) To what extent are the twins mistaken by</b>				
	Missing data (or opposite sex)	Not at all	Sometimes	Most of the time
Mother	24.7	44.9	29.9	0.5 (4.98)
Father	25.8	36.4	34.5	3.2 (10.32)
Siblings	39.2	40.1	19.1	1.7 (8.00)
Relatives	26.4	19.3	27.3	27.1 (6.58)
Teachers	38.3	14.2	24.6	22.8 (8.38)
School friends	37.8	20.7	27.6	13.9 (6.19)
Strangers	26.8	10.5	12.7	50.0 (4.22)

Numbers in brackets are the MZ/DZ discriminability ratio described in text.

The situation becomes even more complex when one moves beyond the family to teacher's assessment of zygosity as in Table 4, which comes from the "Twins in School" project. While registries have traditionally not utilised teacher reports, teachers are a potentially important source of behavioural information, for they do see young twins in a different context from the family and one where they are hopefully less influenced by stereotyped views of what children should be like [1]. Yet, disparities clearly exist both within parent and teacher report (part a of the Table) as well as between the parent and teacher (part b) and between this Table and Table 2 from the ATR survey. In Table 2, a disparity existed in only 12.2% of twins between the two parental questions, whereas in Table 4

the corresponding figure is 26%. The difference may reflect the differing contexts in which the questions are being asked. The ATR questionnaires explicitly refer to genetic research and the comparison of MZ and DZ pairs, while the "Twins in School" project indicates much more concern with the needs of multiple birth families and does not emphasise accurate zygosity. Nevertheless, the differences are disturbing: there were 111 twins who the teachers regarded as very alike, but who the parents considered to be nonidentical and 109 (of these 111) only to show normal family likeness.

**Table 4 - Comparison of parent and teacher replies on two zygosity questions in the "Twins in School" project**

(a)	Parent		Teacher		
	Identical	Non-identical	Identical	Non-identical	Not seen
Alike as two peas in a pod	292	90	502	62	94
Of ordinary family likeness	116	294	36	647	160
Unknown			0	25	9

  

(b) Comparison of parent's view of zygosity and teachers' views	Teacher	Parent		Parent	
		Identical	Non-identical	Peas in a pod	Ordinary likeness
<i>Question 1</i>					
Identical		305	48	265	84
Non-identical		27	490	51	464
Unknown		57	118	50	129
<i>Question 2</i>					
Alike as two peas in a pod		341	111	334	109
Of ordinary family likeness		39	554	74	529
not seen		0	25	0	25

Because many children were separated in school and different teachers would report on the two twins, the teacher data here are based on the number of children and not on twin pairs.

The basis for such a discrepancy may well lie in the parents' greater sensitivity to differences between their children. What is needed is accurate zygosity assessment to confirm such questionnaire diagnoses. To date, no such study has been done, although data will become available from two current projects using the ATR as a source of child and adolescent subjects where bloodtyping is being carried out. The development of analytic methods in quantitative genetics which assess the contribution of specific marker loci [19] may have the indirect benefit of providing such data. In the meantime, the message is that questionnaire assessment of zygosity in children should be regarded more cautiously than is the case with adult twins.

## REPORTS OF SCHOOL PERFORMANCE IN TWINS

The reason for discussing school performance is not because this measure should be an integral part of all surveys of twin children. Rather, it is an example of the sort of data which can be obtained from the separate sources, parents and teachers, with their views confirmed by independent assessment using formal measures of ability and achievement. In addition, the resurgence of interest in Australia for large-scale assessment procedures for school children does mean that these are among the few measures one can expect to be obtained on representative samples of twins and singletons. The creation of such good baseline data would permit the development of means of correcting for the biases inherent in the more usual volunteer twin samples, analogous to those developed for adult twins [16].

The adequacy of teacher report of twins' ability and school behaviour have been proven in previous reports on the ASSP. Teachers were fairly accurate at identifying which twins and singletons needed help with literacy and/or numeracy skills [9]. There, the distinction was made between needing and receiving intervention, since particularly in secondary schools, there are many adolescents who need but do not receive help. Some validation of the teachers' comments comes from the discriminant function comparison of those twins and singletons who failed to achieve mastery of literacy [10]. Teachers' reports featured as highly [10] among the best discriminators as any of the measures derived from the formal ability tests, although the specific variables differed between the four main groups. For the 10-year-old boys, reports of "demanding attention" and "uncooperative with peers" were among the main discriminators, and for the girls "reading reversals" and "hearing problems". At age 14, teachers' reports of "speech problems" were

**Table 5 - Comparison of parent and teacher comments on twins' need for extra educational help in "Twins in School" Project**

**(a) Percentage of twins needing extra help, as reported by parents and teachers**

Area where help needed	Parent		Teacher	
	One twin	Both twins	One twin	Both twins
Speech	9.8	6.9	10.0	9.0
Writing	14.2	10.8	13.1	12.8
Reading	16.2	13.3	18.2	12.3
Number	12.7	10.3	13.9	10.3

**(b) Percentage of twins receiving extra help, as reported by parents and teachers**

Area where help needed	Parent		Teacher	
	One twin	Both twins	One twin	Both twins
Remedial maths	5.0	3.0	4.7	3.1
Remedial English	6.1	4.1	7.0	4.9
Extra small group work	8.6	7.4	11.0	11.5
Speech assessment	8.7	8.4	7.3	6.5
Psych. evaluation	4.3	2.5	4.3	2.2

the most important twin-singleton discriminator in the boys, while “demanding attention” mattered for the girls.

As Table 5 shows, there is considerable consistency between parents and teachers on which twins need extra help. The one difference significant at  $P < 0.05$  is that more teachers perceive both twins, rather than one, as needing intervention with their speech, which may reflect parents’ comparisons of the speech of their twins: because one is “better” than the other, they may consider this child does not need help. There is less consistency in the reports of who receives help (part b of Table 5). As indicated elsewhere [6], this may be because parents take children to speech therapy outside school hours and so the teacher is unaware of this, and similarly, there may be a lot of small group intervention within the school system of which the parents are unaware.

**Table 6 - Australian NHMRC Twin Registry Survey of Twin Children: Major problems reported by parents**

	No problem	One twin	Both twins
Asthma	992	38	78
Chronic bronchitis	1150	30	25
Hyperactivity	1157	28	20
School phobia	1180	17	8
<i>Receiving help from:</i>			
Speech therapy	1034	102 (8.5%)	69 (5.7%)
Physiotherapy	1125	62	18
Psychology	1174	24	7
Audiology	1124	51	30
Ophthalmology	1107	65	33
Remedial reading	1086	69 (5.7%)	50 (4.1%)
Remedial maths	1139	46 (3.8%)	20 (1.6%)
Special class	1161	31	13
Repeating grade	1135	29	41
Special school	1196	8	1

Percentages in parentheses are for comparison with Table 5.

The ATR data in Table 6 indicate that the prevalence figures in part b of Table 5 can be replicated in a different sample. The figures are somewhat lower, reflecting both the wider age-range in the ATR where some children would not have reached an age where help is appropriate, and also the more selected sample which comprises the ATR. If one has a disabled twin or twins, then one may be interested in the educational issues in “Twins in School” but less prepared for them to be involved in more general research. Thus, given the number of twin pairs in the ATR, the number reported by parents as being in special school is much less than would be anticipated.

While there seems to be much consistency between parents and teachers in the proportion of twins identified on different features of their school performance, Table 7 presents a very different perspective. The rates may be the same, but in every area of intervention there are more twins where they disagree than agree.



Thus, in speech, teachers consider 11.8% of twins need intervention and parents 12.3%, but it is only in 5.9% that they both agree on a particular child.

**Table 7 - Comparison of parent and teacher reports in the "Twins in School" program on whether a particular child needs (Y) or does not need (N) intervention in different areas**

Area where help needed			Teacher	
			Y	N
Speech (N = 894)	Parent	Y	5.9	6.4
		N	5.9	81.8
Writing (N = 912)	Parent	Y	9.3	8.7
		N	7.9	74.1
Reading (N = 937)	Parent	Y	13.1	8.5
		N	7.3	71.1
Number (N = 910)	Parent	Y	8.6	7.9
		N	7.8	75.7
Motor (N = 874)	Parent	Y	2.5	3.9
		N	5.1	88.5

Table 8 offers an explanation of this in terms of educational philosophy, using data from the LTS where there are more formal measures of reading ability. The Neale Reading Test describes a child's ability in three main areas, reading rate, accuracy and comprehension. From Table 8, it is clear parents put more emphasis on reading accuracy and that the child does not make mistakes in what they read. On the other hand, the teacher is more interested in that they understand what they are reading and does not give the same emphasis to textual mistakes. That is, in identifying who needs intervention, the two groups use different criteria. As Table 7 showed, this may mean parents and teachers perceive a similar number of children may need help, but they need not be the same children in the two cases.

**Table 8 - Proportion of parents and teachers in the LaTrobe Study reporting twins as needing remedial reading, compared with the discrepancy of the children's Mental Age (MA) on the Neale Reading Test from their Chronological Age (CA)**

	Reading accuracy MA		Reading comprehension MA	
	≤ 1 yr of CA (N = 41)	> 1 yr behind CA (N = 21)	≤ 1 yr of CA (N = 43)	> 1 yr behind CA (N = 19)
Parents	21.6	69.2	17.4	58.3
Teachers	18.5	47.2	22.6	73.8

## WHAT IS ESSENTIAL INFORMATION FOR A TWIN REGISTRY?

A volunteer registry which collects information mainly by mail has two conflicting aims: to collect the maximal amount of data in a questionnaire which is not so long that it deters many of the respondents. The reason for including so many tables in this article is to provide some indication of which questions work, in that they are answered reliably by a reasonable proportion of the population. Thus, Table 3 and the MZ/DZ index give some indication which of the many possible questions on zygosity are worth including. Similarly, the four questions (asthma, bronchitis, hyperactivity and school phobia) at the top of Table 6 are the only ones of many on health-related issues which are answered by enough of the population to warrant inclusion in a large-scale questionnaire survey.

**Table 9 - Recommendations for questions for routine inclusion in Twin Registry surveys**

Pre- and perinatal	Bedrest Natural, fertility drug or IVF pregnancy Length of pregnancy Complications of pregnancy, especially pre-eclampsia Complications of delivery (breech, cesarian, etc) Birthweight Days after delivery when twins came home, together or apart
Zygosity	Belief about twins' zygosity Likeness
Family details	Other children Language spoken at home Divorce
Health of twins	Asthma and bronchitis, epilepsy, hyperactivity, autism, leukemia, hernia, cardiac problems Congenital anomalies, cerebral palsy, intellectual disability, sensory deficit
Remediation	Speech, audiology, reading, maths, repeating grade
Intrapair comparisons	Ability, coordination, independence, extent of separation
Psychometric tests	Mother's General Health Questionnaire (12 item) Temperament Mini Childhood Behaviour Checklist [2]

Table 9 is an initial attempt at what information should routinely be collected on child twins. Experience in the ATR has indicated that, unlike the other complications whose incidence is elevated in multiple pregnancy [3], only pre-eclampsia is reported with sufficient reliability and frequency by mothers of twins. Obviously, cesarian section is common, as are breech presentations especially in the second born. Because bedrest and access to neonatal intensive care may be limited by practical or economic constraints, the issue of the twins' status is addressed by when they came home from hospital.

The reason for such information is not to rival the multiple pregnancy data collected in such focussed projects as the East Flanders Prospective Twin Survey [24,25]. Rather, it provides some minimal basis for issues which may affect parental perceptions of the twin pair [8] or, as in the case of twins who come home from hospital at different times [11], which may accentuate perceived differences within the pair.

The sections on zygosity and remediation or the perceived need for remediation follow the earlier discussion. It is important to know of other siblings, if only because of the possibility of extending genetic designs beyond twins [8]. Knowing about divorce matters also for any proposed twin-family design which relies upon access to both parents or for where information about the children is being collected from both parents. In a country as culturally diverse as Australia, many families speak some other language than English at home. In our experience, this can be associated with a higher incidence of language problems in the twins, as well as being information of practical value if one is dealing with parents whose English is poor.

It would be easy to devise a lengthy list of health-related issues, but this could be counterproductive if the length of the list deterred its completion. The list here covers the main areas where a higher incidence of problems has been reported in multiples, even though it can take a very large population-based survey to detect any significant twin-singleton difference in incidence [13]. It is appropriate to know if a twin has a particular anomaly, if only so that they are not invited to participate in any planned follow-up from which their disability would preclude them. In our experience, it is better to have the informant write in the medical details, from which they can later be coded, than to use a checklist of possible disorders.

The section on intrapair comparisons is the outcome of three related observations in behaviour genetic research. Firstly, measures of closeness between twins have only a modest relationship to differences in IQ [22] and certainly counter critics who emphasise the role of this variable. Secondly, there is a variety of behavioural measures in adult twins where intrapair similarity is a function of how long they have lived in the same household [12]. One important analogy with children is whether there has been a period when they have been reared apart. This is perhaps less unusual than it may appear. In our clinical work, we have now encountered more than ten pairs of adolescent twins where the friction in the family was so bad that one was sent to relatives or to boarding school. Thirdly, is the point made earlier in describing some of the school report measures that parents can stereotype and exaggerate differences between twins: when this happens in MZ pairs, any genetic factors will be underestimated [11].

The final section is more speculative and parallels the previous work with adults in the ATR where fairly basic psychometric instruments completed by so many twin pairs have been the basis for some important genetic work [eg, 15]. One is really looking for a screening instrument which could be supported by subsequent follow-up in more detail. The two childhood measures which would be most important concern temperament and behaviour problems. Measures of temperament have come under increasing scrutiny [26], but short forms such as those used in the

Australian Temperament Project have better psychometric properties than some of the older, lengthier versions. Similarly, the short forms of the Achenbach Childhood Behavior Checklists developed for the large Ontario child survey [2] do focus on just the major indicators of frequent psychopathology and have high reliability. The maternal General Health Questionnaire (GHQ) is included because both the temperament and behaviour checklists are based on parental ratings of the child and one has the dilemma of whether the responses say more about the rater and their psychological state than about the child [26].

Whatever instruments are used, our experience has revealed a particular bias. Parents of twins are generally prepared to complete questions which they see are of relevance to twins. It is a different matter when it comes to temperament and the often fairly negative behaviour problem checklists, both developed around the needs of singletons. While this point applies especially to psychometric instruments, it is of general relevance to any questions in a twin registry where one is trying to obtain information from many families who may have little commitment to research.

## CONCLUSIONS

A major question exists over why one may want to collect so much information on so many twins and leads to an evaluation of the purpose of a twin registry. If there is a very specific project in mind, then much of this information is irrelevant and the twin families one recruits are likely to be interested in this particular issue and very compliant at completing lengthy and sometimes very invasive questionnaires. The ATR is the opposite and represents a philosophy where the collection of general information may motivate the involvement of a researcher to study this topic in more detail. It is clear by the comparison of some of the information collected in the ATR and the "Twins in School" project that the very different emphases of the two projects can lead to very different response patterns in what should be similar samples, ie, volunteer groups from within the same country collected at about the same time.

It should be emphasised again that this situation is quite different from that of adult twins where one can correct for differential enrolment based upon the features of the two twins: in the case of children, one is working with parental biases and the issue of whether one or both twins are affected may have less bearing on enrolment. It does mean that one is not so much concerned with differential rates of reporting as with the question of who is reported. Parents may choose to report one twin rather than both and may use a different set of criteria from teachers.

A final point is that one is dealing with children who are developing. This has two implications. Questionnaires may have to be tailored more to the needs of specific age-groups in a way that is not so necessary with adults. Thus, the ATR is developing a "Baby Baseline". The other issue concerns when families enrol their twins: is it at birth or later, when a problem has become more obvious? In the LTS, time of enrolment can be determined by the order of the family code number. Families who enrol later have twins with a larger variance on many psychomet-

ric measures. That is, more are enrolling because their twins have problems and they want help or because their twins are doing much better than other twins and they want this confirmed. Selective attrition or the effects of information given to minimise such attrition can complicate the situation even further [8].

One may begin to wonder if registries should even contemplate collecting data on twin children or should continue to focus on adults. If one were to do this, one would be neglecting the resource of a large group of parents often strongly committed to having their twins help research. One would also have adult twins where little was known about their earlier history. It is to be hoped that twin registries will draw increasingly upon child twins and that cumulative experience will answer some of the issues raised here.

**Acknowledgments.** The LaTrobe Twin Study and the Australian Twin Registry are supported mainly by the National Health and Medical Research Council (Australia).

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