

New cross sectional stature, weight, and head circumference references for Down's syndrome in the UK and Republic of Ireland

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Arch Dis Child 2002;**87**:104–108

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Accepted
21 November 2001

Aim: To present a growth reference for children with uncomplicated Down's syndrome living in the UK and Republic of Ireland. Data are available for height and weight in the age range 0–18 years, including the first three months of life, and for head circumference in the first year.

Methods: The study sample was drawn from 16 discrete geographical areas and was representative of children age 19 years of age or less who are now living in the UK and Republic of Ireland. Multiple growth measurements for 1507 children were obtained retrospectively by case note search. Data from children with significant cardiac or other major pathology were excluded from analysis. Data from pre-term babies were excluded up to age 2 years. Centile curves were constructed from 5913 selected measurements from 1089 children and were derived using Cole's LMS method.

Results: The resulting centiles differ substantially from those previously available in the UK, which were based on selective US data published in 1988.

Conclusions: We propose that these charts should now be adopted as the standard UK/Republic of Ireland reference.

Short stature is a recognised characteristic of most people with Down's syndrome. Average height at most ages is around the 2nd centile for the general population. For the majority the cause of growth retardation is not known.¹ Some conditions leading to poor growth (congenital heart disease,^{2,3} sleep related upper airway obstruction,⁴ coeliac disease,^{5,6} thyroid hormone deficiency,^{7,8} and nutritional inadequacy caused by feeding problems^{9,10}) occur more frequently among those with the syndrome. There is also a high prevalence of overweight/obesity, particularly in adolescence and adult life.^{11,12} However, people with the syndrome are not necessarily overweight in relation to their height. As with the general population, weight is influenced by environmental^{12,13} as well as biological factors,¹⁴ and for most, preventive measures are both feasible and effective.

Regular growth surveillance of children with Down's syndrome should aid early identification both of pathological causes of growth retardation and of incipient overweight/obesity. Growth charts are recognised as a useful tool for monitoring the growth and wellbeing of children. However, where normal growth patterns differ from the general population, it has been found useful and clinically important to use syndrome specific growth charts.¹⁵

The Down's syndrome growth charts in current use in the UK were produced by Cronk and colleagues,¹⁶ based on US data published in 1988.¹⁷ As with the general population, height of those with Down's syndrome varies from country to country. Those in the Netherlands are taller than those in the USA and much taller than those in Sicily.^{18,19} In addition the US data were derived from five different clinic or research based samples. The study sample was therefore not representative of the total population. Furthermore no exclusions were made on the basis of either coexistent major pathology (for example, cardiac or thyroid disease) or gestational age at birth. We therefore identified a need for a contemporary UK growth reference for children with uncomplicated Down's syndrome.

SUBJECTS AND METHODS

Ethical approval was obtained from the South Thames Multi-centre Research Ethics Committee and from local research ethics committees.

Data collection

Community paediatricians in the UK and Republic of Ireland were approached through personal contact or by advertisement at national paediatric meetings, to see whether they had adequate special needs registers to identify all the children with Down's syndrome in their geographical area. Sixteen such areas were identified: one each in the Republic of Ireland, Northern Ireland, and Scotland, and the remaining 13 in six of the eight geographically determined health regions in England.

All relevant medical records were searched by the local paediatrician or one of the authors (MS). Children were given an anonymous identification number. All records of height, weight, and head circumference were collected, together with the method and date of measurement, date of birth, sex, and gestation. Ethnicity was not consistently recorded in the source records, but assuming that in such cases the child was white, 94% of the sample was white. A record was also made of any coexisting illness (for example, heart disease, bowel disorder, or malignancy); the date and result of the most recent thyroid function test was also recorded. In addition data were incorporated from a cross sectional population based growth study in the Eastern Health Board area of the Republic of Ireland.²⁰ To aid centile construction for the later teenage years, a further 27 young adults, aged 20–24, were recruited from a further education college, giving a total study population of 1507.

To avoid any child being over represented in the dataset, not more than two measures per year were included for children over 1 year and not more than four measures in the first year. A total of 8818 measurement episodes were entered into the dataset; 96% of children identified through the special conditions registers provided data.

Table 1 Frequencies of measurements by age and sex

Age (y)	Male	Female	Total
0	810	673	1483
1	281	246	527
2	269	246	515
3	244	239	483
4	221	204	425
5	192	176	368
6	160	164	324
7	143	133	276
8	131	122	253
9	113	109	222
10	114	106	220
11	103	84	187
12	81	58	139
13	70	68	138
14	55	58	113
15	44	38	82
16	37	27	64
17	20	17	37
18	11	12	23
19	5	2	7
20	6	6	12
21	3	9	12
22	2	0	2
24	0	1	1
Total	3115	2798	5913

Excluded children

Data for dead children still on the special needs register were excluded. Data from those with coexistent major pathology and/or preterm birth (less than 37 completed weeks gestation) were excluded as follows. Those with no abnormality or a small atrioventricular or ventricular septal defect, or a patent ductus arteriosus that had already closed or was asymptomatic were included in the study; those with a higher score or history of cardiac surgery were excluded. In addition children with other multiple or major pathology were excluded. Measurements for children born preterm were excluded for the first two years of life, but later measurements were included.

Measuring techniques

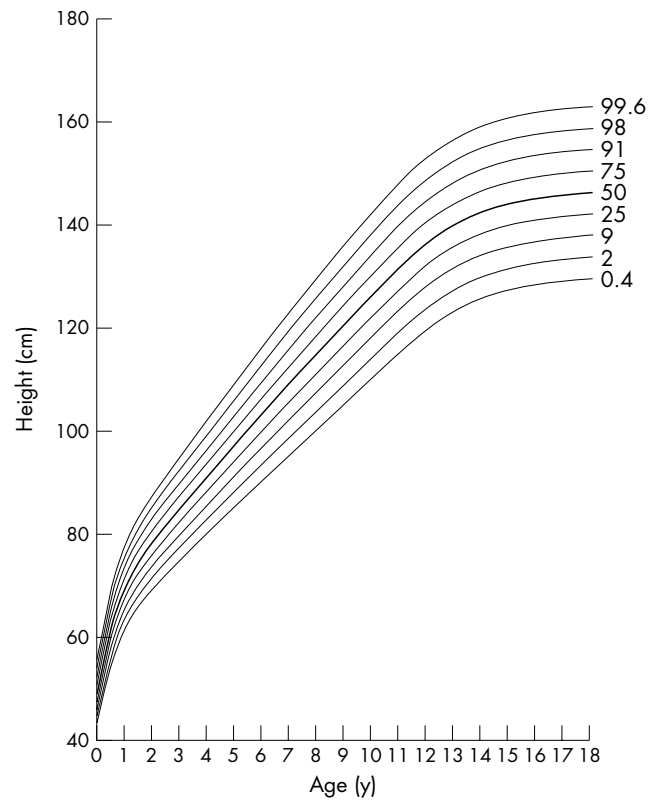
Reported measuring techniques were variable over time both within and between areas. In most areas staff had been trained, including paediatricians, clinic nurses, health visitors (more frequent in the under 5s), and school nurses (more common in the over 5s). Infants were weighed naked; older children were measured without footwear in underwear or light indoor clothing.

Equipment varied between and within areas. Standard clinic equipment included regularly calibrated scales and stadiometers. Community staff often used portable equipment that was less often calibrated.

The data collected between age 1 and 5 years contained measures of both supine length and height, because the age at which children with Down's syndrome can stand unaided is extremely variable

Statistical analysis

Data were cleaned in several stages. Bivariate plots of height, weight, and head circumference were used to identify gross disproportion. Data points so identified were scrutinised, going back to the source data if necessary, and transcription errors corrected. If a value was deemed highly unlikely (more than 5 SDs from the mean), but if there was no evidence of a transcription error, the point was deleted. In addition, runs of individual longitudinal data were scrutinised for evidence of unlikely measurements, such as apparent loss of height, and where possible, edited.

**Figure 1** Girls' Down's syndrome height chart for the UK and Republic of Ireland.

Centile curves were fitted to the data using Cole's LMS method.²¹ Briefly, this assumes that the data can be transformed to normality by a suitable power transformation (L), and the distribution is then summarised by the median (M) and coefficient of variation (S). The values of L, M, and S are constrained to change smoothly with age, and the fitted values can be used to construct any required centile curves. Cole and colleagues²¹ give more details.

RESULTS

A total of 407 children were excluded because of cardiac disease or other major pathology. Of those remaining, 138 were preterm; 11 of these had no data after age 2, hence were excluded. After exclusions, the final sample consisted of 1089 children (597 boys and 492 girls). There were 5913 occasions with at least one valid measurement, providing 5681 weights, 4941 heights, and 2364 head circumferences. Table 1 gives the numbers of measurements by sex and year of age. A quarter of all measurements were in the first year of life, while there were relatively few points after 14 years of age.

Some subjects were measured on more than one occasion; one third of subjects provided just one measurement, representing 6% of all measurements. At the other extreme, 15 children each provided 20 or more measurements. The 868 subjects with between one and nine measurements provided half the total, the other half coming from the remaining 221 subjects with 10 or more measurements.

Centiles were fitted to the data using the LMS method. For height and head circumference the distribution was assumed normal; for weight there was appreciable skewness and the age varying power transformation was adjusted for it. Using these data, reference charts for girls and boys with Down's syndrome in the UK and Republic of Ireland were constructed using the nine centile curve format proposed by Cole²² and used in the current UK 1990 growth reference²³ (figs 1, 2, and 3).

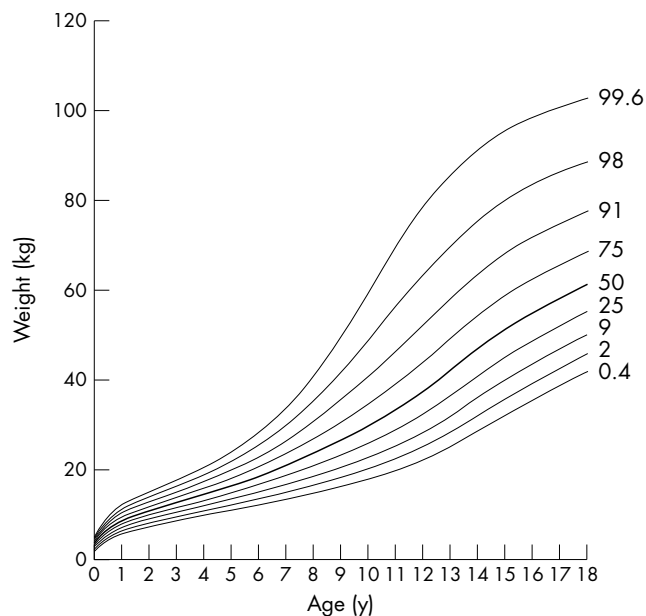


Figure 2 Boys' Down's syndrome weight chart for the UK and Republic of Ireland.

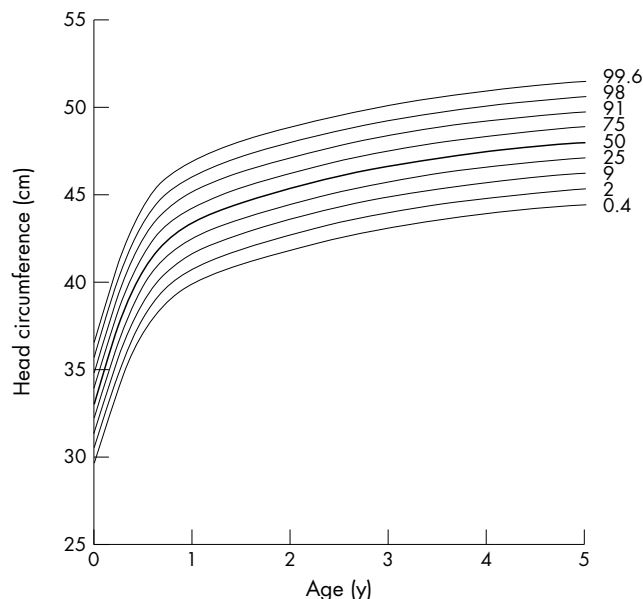


Figure 3 Girls' Down's syndrome head circumference chart for the UK and Republic of Ireland.

DISCUSSION

We have produced the first growth charts relevant to children with Down's syndrome in the UK and Republic of Ireland. While not based on a dedicated sample survey we believe the distribution of the contributing centres to be broadly representative. The advantages of using retrospective data collection rather than performing a prospective study are: firstly, the short time required to collect the data; secondly, the ease of recruiting a whole population rather than a smaller selected group of volunteers; and thirdly, the low cost.

The measuring techniques, equipment used, and personnel involved varied over time, both within centres and between centres. However, the variation we recorded reflects normal practice and for this reason, and because of the large sample size, we consider that the reference is wholly applicable for use in day to day practice. We note too that Cotterill and colleagues²⁴ have shown that trained school nurses are as reliable as auxologists in assessing the height of schoolchildren.

In addition to the main child and teenage data a small number of measures were taken of young adults in order to facilitate construction of the curves in the late teenage years. Although the numbers were relatively small in later years the centile curves throughout childhood, and particularly in adolescence and early adulthood, look sensible, with the height and head circumference centiles flattening off as expected as adulthood approaches.

We believe that the curves reflect an accurate picture of the UK and Irish populations as they are and have been over the past 19 years. We do not propose that they are a standard to be achieved, particularly for weight in the older age groups where it is clear that a significant proportion of the population is obese. The tendency to overweight in late childhood and the teenage years is notable. Our data reveal that 30% of those aged 10 or more have a body mass index (BMI) greater than the 91st and 20% greater than the 98th centile for the general population. We have already mentioned that overweight is not inevitable in this population. For most, as in the general population, due attention to diet and exercise is effective in controlling overweight/obesity. We have shaded the area above the 75th weight centile in the 5–18 age range and referred the user to the UK 1990 BMI chart which we have reproduced on the front cover. We recommend that for the time being, as in the general population, those whose BMI lies above the 98th centile are significantly overweight (obese) and in need of further assessment and guidance, and those above the 91st centile are overweight and should be carefully monitored. It is likely that we will update this recommendation as we evaluate the usefulness of the charts in clinical practice.

Of those falling below the 2nd centile for height and/or weight, some will have major pathology. There is evidence that, as in the general population, those with major cardiac disease will be over represented at the lower end of the charts, as will those with other major pathology. We do not have sufficient data to construct charts for preterm babies and, as in the general population, advise that measurements for those born before 37 completed weeks gestation should not be plotted on the charts until the estimated due date is reached. Thereafter they should be charted relative to estimated due date for at least a year.

Preliminary data suggest that many babies with the syndrome do not regain birth weight until around 1 month.⁹ This is not reflected in the charts because of their cross sectional nature. This early failure to thrive is usually a result of feeding difficulties, many of which resolve after the first few weeks. However, the possibility of major gastrointestinal pathology (duodenal narrowing, gastro-oesophageal reflux) should always be borne in mind. We further advise that from 1 month, in the absence of major pathology, babies whose weight continues to fall through the centiles should have their dietary intake monitored, as ongoing feeding difficulties and failure to thrive are not uncommon in this population.¹⁰

Individual children may show growth spurts and plateaus that are more prolonged than in the general population but which are not reflected in the reference charts. Similarly the charts suggest an absence of the pubertal growth spurt. Those with the syndrome do have an adolescent growth spurt, but it is usually less vigorous than in the general population and in some children may occur at an earlier age.²⁵ When this happens it will impose a limiting effect on final height.

Comparison with the Castlemead/US charts,¹⁶ which have hitherto been the only Down's specific charts available in the UK, reveals notable differences:

- The UK height centiles map fairly closely to the US charts between 3 and 12 years, but subsequently the US centiles drift below the UK charts so that by age 17 the US 50th centile for boys is below the UK 25th and the 25th around the 5th (fig 4). Note the discontinuity in the US centiles at age 3.

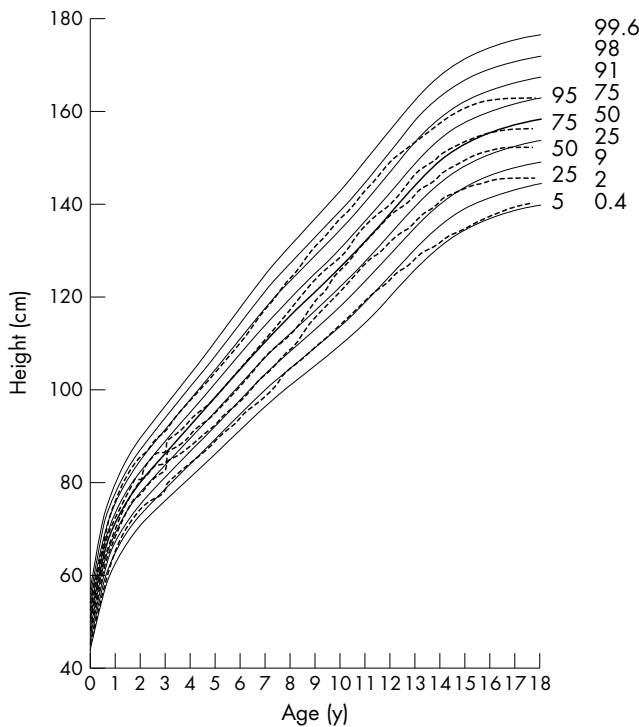


Figure 4 Boys' Down's syndrome height chart for the UK and Republic of Ireland, with the centiles of Cronk and colleagues¹⁶ superimposed.

- US teenage boys thus appear shorter than their UK counterparts (and also heavier, data not shown).
- The median weights for girls are similar on the two charts, but the US charts show far greater variance before puberty and less subsequently (fig 5). The UK data thus support the widespread clinical impression of considerable overweight/obesity in later childhood and adolescence.
- The US charts have no data for the first three months. Past this age the US and UK length centiles are similar, but the UK weight centiles are appreciably higher, reflecting the absence of preterm births and major pathology. For instance at age 1 the US 5th girls weight centile falls on the UK 0.4th, and the 25th on the 5th. The boys are similar. This means that if the US charts are used to assess babies with uncomplicated Down's syndrome, an appreciable number of those with failure to thrive (see above) will remain undiagnosed.

The charts based on these data are printed for clinic (A4) and parental (A5, Personal Child Health Record format) use in the 9 centile format proposed by Cole.²² Following consultation with parents and doctors, the 0.4th, 50th, and 99.6th centiles from the 1990 UK growth reference are overprinted on the A4 charts to facilitate comparison with children without Down's syndrome.

Conclusion

We present for the first time centile charts for weight, height, and head circumference appropriate for children with Down's syndrome living now in the UK and Republic of Ireland. Those with the syndrome show different biologically determined patterns of growth from the general population; in addition, a range of both major and minor pathologies may further compromise growth. Growth surveillance throughout childhood will aid in the early identification of a range of pathologies and in the prevention of overweight and obesity, and can be best achieved by using syndrome specific charts. The charts presented here are more informative and accurate than the earlier US charts currently in use in the UK and Republic of Ireland. Differences throughout the age range have significant

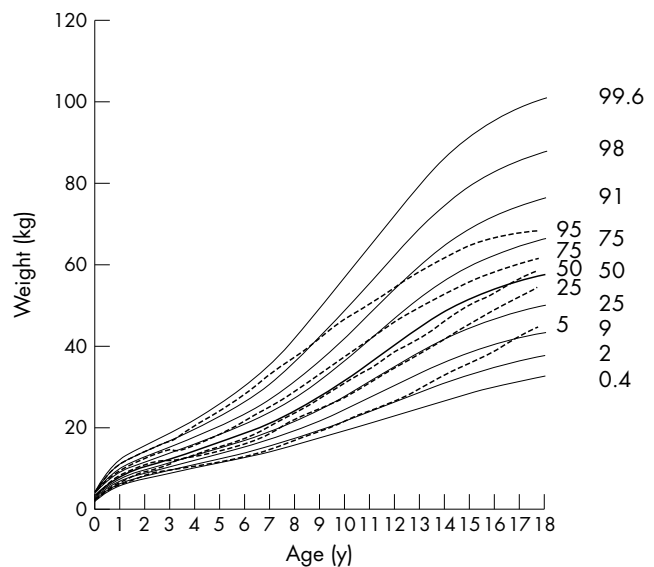


Figure 5 Girls' Down's syndrome weight chart for the UK and Republic of Ireland, with the centiles of Cronk and colleagues¹⁶ superimposed.

clinical implications. We therefore urge that use of the US charts should now be discontinued and recommend that the new charts are adopted as the standard reference for these two countries. The charts are published in A4 format for clinic use and in A5 format for use within the Parent Held Personal Child Health Record. They are therefore available for use in everyday clinical practice.

ACKNOWLEDGEMENTS

We would like to thank the Down's Syndrome Medical Interest Group for initiating this project and for support throughout, and the many community paediatricians who were involved in the time consuming task of data collection. We are also grateful to Tam Fry and the Child Growth Foundation for support, encouragement, and for covering travel expenses (MS), and John Short and his team at Harlow Printing for steering through the final production of the charts. Copies of the A4 charts and the PCHR inserts are available from Harlow Printing, Maxwell Street, South Shields, Tyne and Wear NE33 4PU, UK.

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POSTCARD FROM DOWN UNDER.....

Is this a Pom I see before me?

How do you define nationality? For some I imagine that this is fairly straightforward. I find it a little more challenging. I know that I'm English, because I was born in England. In some parts of the world it is easiest to define oneself as English because being British is apparently synonymous—and somehow less clear. The phrase "Ah, English...Manchester United!" must be taught in schools around the world. I know that being English makes me British, but I also know that my country of origin—on official forms—is better described as UK, as this describes the United Kingdom of Great Britain and Northern Ireland. Besides, despite being happy to write British, I feel a certain pompousness about writing the "Great" in Great Britain: I can hear Cilla Black (an English 60s pop idol still going strong as a TV host) expressing the view that (referring to Margaret Thatcher) "Maggie put the Great back in Great Britain" and I shudder a little. Sometimes I look at my National Training Number and at my burgundy coloured passport, and at that point I know that I'm a European, but I have really no idea what that means.

My colleagues and friends here are in no doubt that they are Australian. The majority of them are Queenslanders too, of which they are doubly and distinctly proud. Pride is a concept writ large in the Australian psyche, and sometimes overused to the point of ridiculousness. For example, a fast food chain does not simply sponsor a children's soccer tournament: it "Proudly Sponsors" it, failing to see—or perhaps cynically exploiting—the strange juxtaposition between fast food and sport.

There are many things of which I feel proud, but I hesitate to use the word, in the same way that I flinch from the "Great" in Great Britain. This time, instead of Cilla I see a racist thug—or worse, a racist intellectual—saying that "We should be proud of our race," or some such meaningless garbage.

The urge to generalise from specifics is almost overwhelming. I've done it at least once already here, arguably two or three more times, and will do it again before I finish. Inferring a general rule from a specific interaction must have been essential for our survival: for example "These berries are good to eat. Those berries are not." Fast forward an

indeterminate amount of evolution to medical school, and here you have classification and generalisation raised to a fine art: "These children develop asthma," "These children have lower IQs," and so on.

Trying to teach myself to spot generalisations has been much less easy than I'd thought, because many are wrapped up in pseudo-intellectual justification or compliment. For example, any statement starting with: "Australians are . . ." has to be suspect unless it is followed by a strict statistical or geographical definition. Just substitute it with "Black people are . . ." or "Jewish people are . . ." and perhaps you'll begin to see the flaw. At a more trivial level, I often find myself saying "Cyclists are . . ." or "Paediatricians are . . ." Of course, these statements are nowhere near as offensive as overtly racist comments, but at the same time they can easily include the same crass generalisations.

(In case you are interested, to Australians: "Poms are . . .infrequent bathers." Apparently we get by on only one bath a week, which seems like sheer indulgence to me. Pom, incidentally, is derived either from pompous, or from Prisoner of His (Her) Majesty; take your pick).

To begin to turn this full circle: An Australian can be wholeheartedly proud to be an Australian, at the same time as disapproving of Pauline Hanson—right wing leader of the One Nation political party, mandatory sentencing, or the Australian Government's handling of the MV Tampa stand off. This leads to an oddly circular situation, central to any nationalistic feeling, where the proud national makes a broad generalisation, whilst recognising that the generalisation is immediately and profoundly flawed.

Where does that leave me and my Englishness/Britishness/Europeanism? I don't think I'm any the wiser, and I suppose I will continue to define myself depending on the circumstances, while harbouring a certain jealousy for the folk who see things more simply. However, I must leave this here, as there is an "a" in the month, and so it is time for my bath.

I D Wacogne

Dr Wacogne was on secondment at the Royal Children's Hospital, Brisbane for two years and is now completing his SpR training at the North Staffordshire Hospital, UK.