INTERNATIONAL BENCHMARKING FROM CENTRE-LEVEL CYSTIC FIBROSIS DATA

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1. Background

Developments in national cystic fibrosis (CF) data registries are creating opportunities to compare patient outcomes and clinical practice between treatment centres. The patient registry of the United States (US) Cystic Fibrosis Foundation (CFF) has been used effectively for the identification of best practice care (Gawande 2004, Schechter and Margolis 2005).

Smaller national registries do not have the numbers to deliver such benefits on a similar scale. For this reason, international benchmarking at centre level is of interest. Arrangements for sharing a limited range of indicators, which have been in place over recent years between the US and Australian registries (PortCF and ACFDR respectively), illustrate the benefits.

2. Objective

To extend to an international level the benefits obtainable from centre-level benchmarking of CF patient outcomes.

3. Methods

A short list of indicators that are widely used for monitoring patient outcomes has been proposed, along with standard methods of construction and common disaggregation for risk adjustment (Sims 2009). Lung function and nutrition are the most frequently measured concepts for individual and group (including treatment centre) patient outcomes. For the derived statistics on which lung function and nutritional values are compared, the US and Australian registries use common methodology.

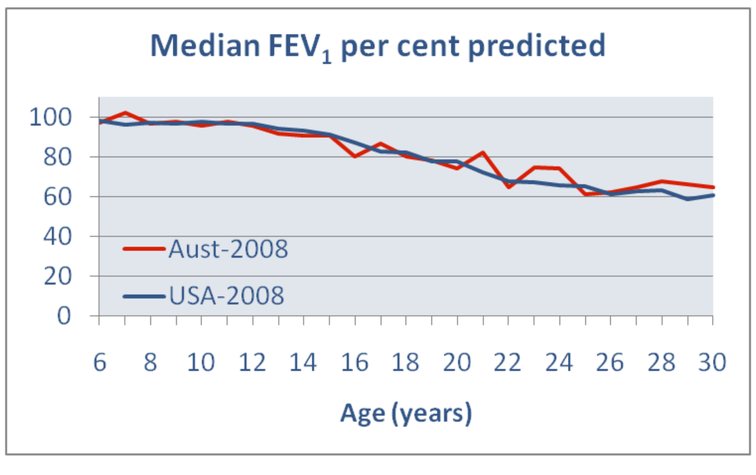
Specific indicators are per cent of predicted FEV_1 (FEV_1 % predicted), Body Mass Index (BMI) for adults and, for children and adolescents, BMI percentiles. Statistics at centre level are calculated from registry data, excluding centres with fewer than 10 patients in any category. FEV_1 % predicted is calculated for males aged 6 to 17 years and females 6 to 15 years from the formulae of Wang et al (1993) and from the formulae of Hankinson et al (1999) for older persons. Anthropometric reference values used in percentile calculations for children and adolescents are from the CDC 2000 series. BMI is used to compare nutritional values in adults.Patients who have had lung transplants are excluded from both US and Australian data sets.

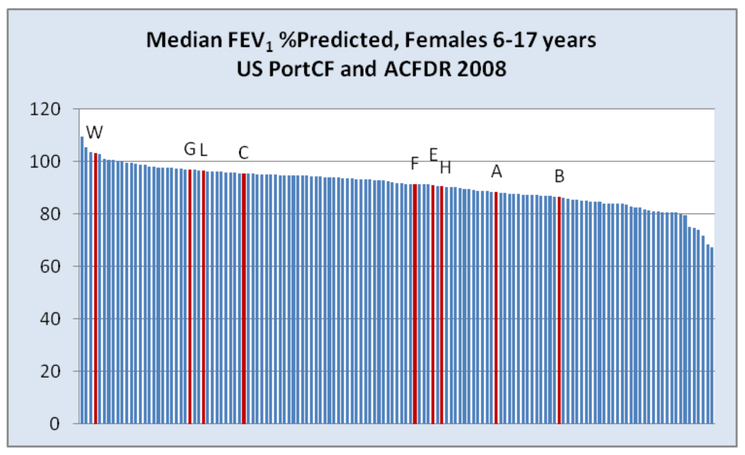
Column charts for the selected indicators show median values in 2008 for US and Australian centres, overlaid in sequence from highest to lowest, with Australian centres distinguished by a different coloured bar and identifed by a code that is known to Australian Centre Directors.

4. Patient outcomes: lung function

A comparison with latest age-based lung function data from the US (CFF, 2009) shows Australian and US patients at similar levels across a broad age range.

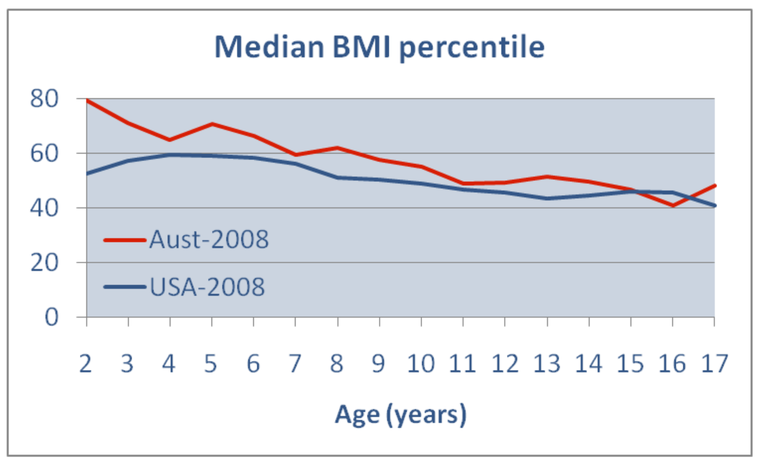
Consistent with this, the distribution of median values across treatment centres in Australia is not dissimilar from those calculated for US centres, though their number is much smaller (top of second column). The pattern for males is similar.



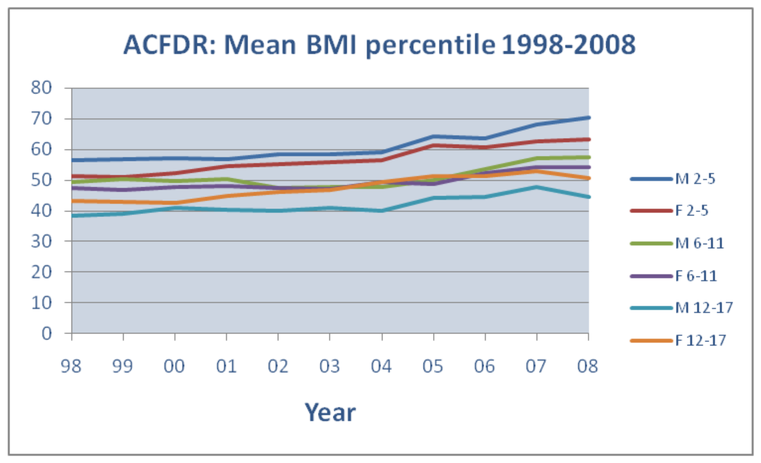


5. Patient outcomes: nutrition

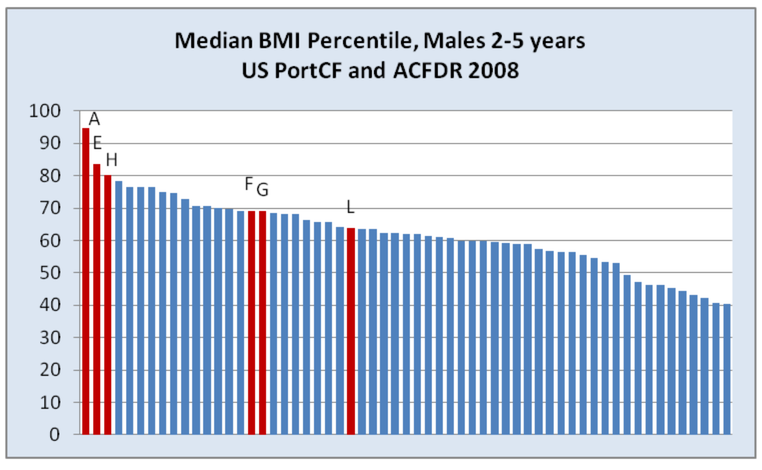
In the case of child and adolescent nutrition, younger Australian children appear to experience better outcomes than their US counterparts.

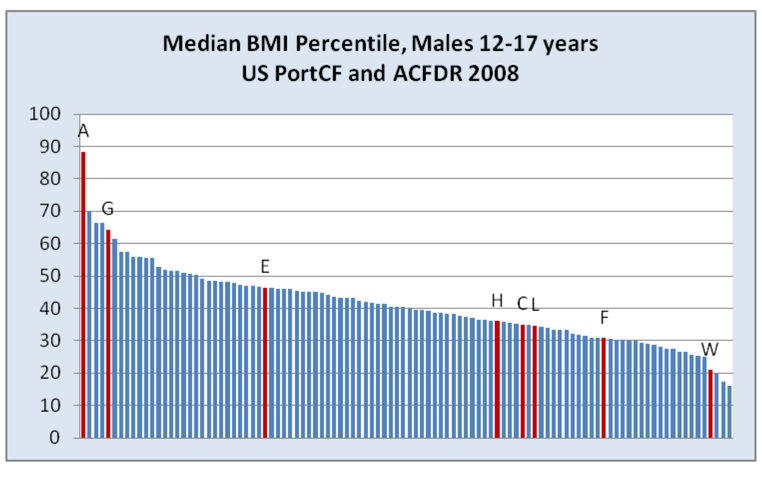


Trends since 1998 in nutritional outcomes for children show improvements in all age and sex groups, becoming more rapid over recent years.



In line with these comparisons and trends, Australian centres are represented in the upper range of two country median values for BMI percentile in young children, as illustrated for males in the following chart. However nutrition values for adolescent males in Australia do not exhibit a similar advantage over US adolescents (below).





6. Discussion

Benchmarking raises questions that suggest supplementary investigation. Examination at centre level allows a focus on variation in patient management at the decision making level. Bringing data from two countries together adds a dimension to the opportunities for benchmarking to help identify best practice, as is evident in the data displayed.

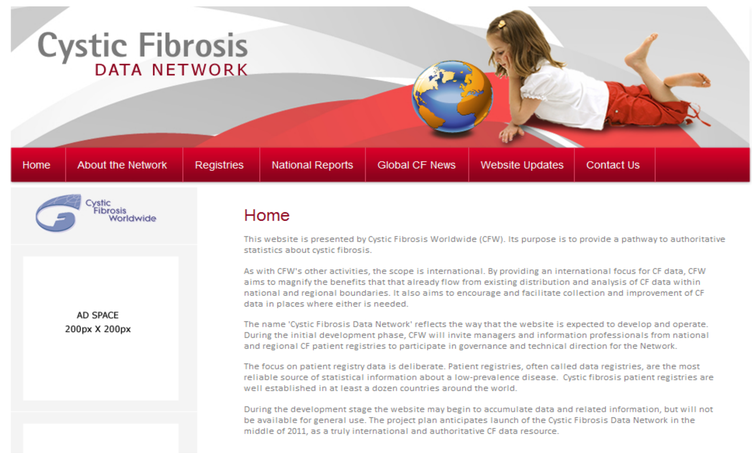
In any benchmarking analysis it must be recognised that other factors have contributed to variation. Sstratification of the indicators by sex and broad age groups goes only part way towards risk adjustment. Questions remain about what factors may explain further differences and what inconsistencies remain in the data, despite use of common definitions and methodology.

In that light, it would be premature to conclude from the brief viewing of these data that Australian paediatric treatment centres approach best practice in nutrition management. A more useful observation would be that opportunity for further investigation is invited by the data. Even from an Australian centre perspective, considerable within group variation remains to be investigated.

7. A proposed CF Data Network

Discussions with stakeholders indicate general support for international collaboration around CF data. A Cystic Fibrosis Data Network (CFDN), operated through a website is proposed. Initially it would provide a portal for access to existing data reports and related 'metadata' and, with cooperation from national registries, offer standardised statistics for demographic and other major characteristics.

Cystic Fibrosis Worldwide (CFW), the peak international body for CF national associations, has agreed to host the CF Data Network under a 'trusted third party' arrangement. During its development phase, CFW will invite managers and information professionals from national and regional CF patient registries to participate in governance and technical direction for the Network. A web-based forum for data standards issues is envisaged. Agreed standards are a prerequisite for multinational benchmarking, which is a longer term objective for the Network.



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