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INTERNATIONAL BENCHMARKING FOR CYSTIC FIBROSIS PATIENT OUTCOMES USING REGISTRY DATA



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1. Why centre level benchmarking?

Developments in cystic fibrosis data registries are creating opportunities to compare patient outcomes and aspects of clinical practice between treatment centres. In fact, the ability to undertake centre-level benchmarking for quality improvement is one of the reasons for the establishment and maintenance of national registries. Comparisons generated at the centre level deliver information that can be used to improve quality of care, as has been described by several authors (Wiedenmann et al 2001, Gawande 2004, Schechter and Margolis 2005).

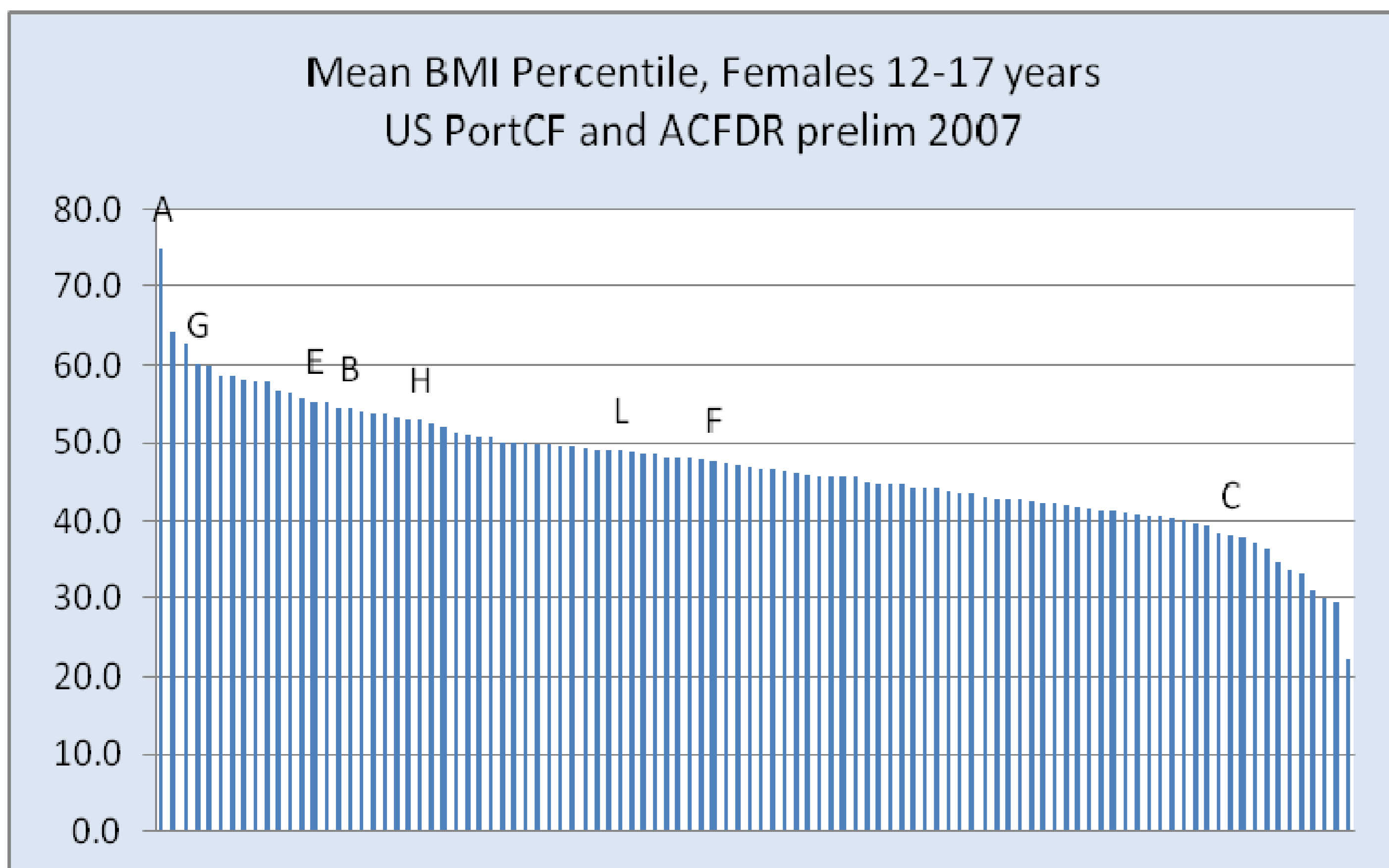
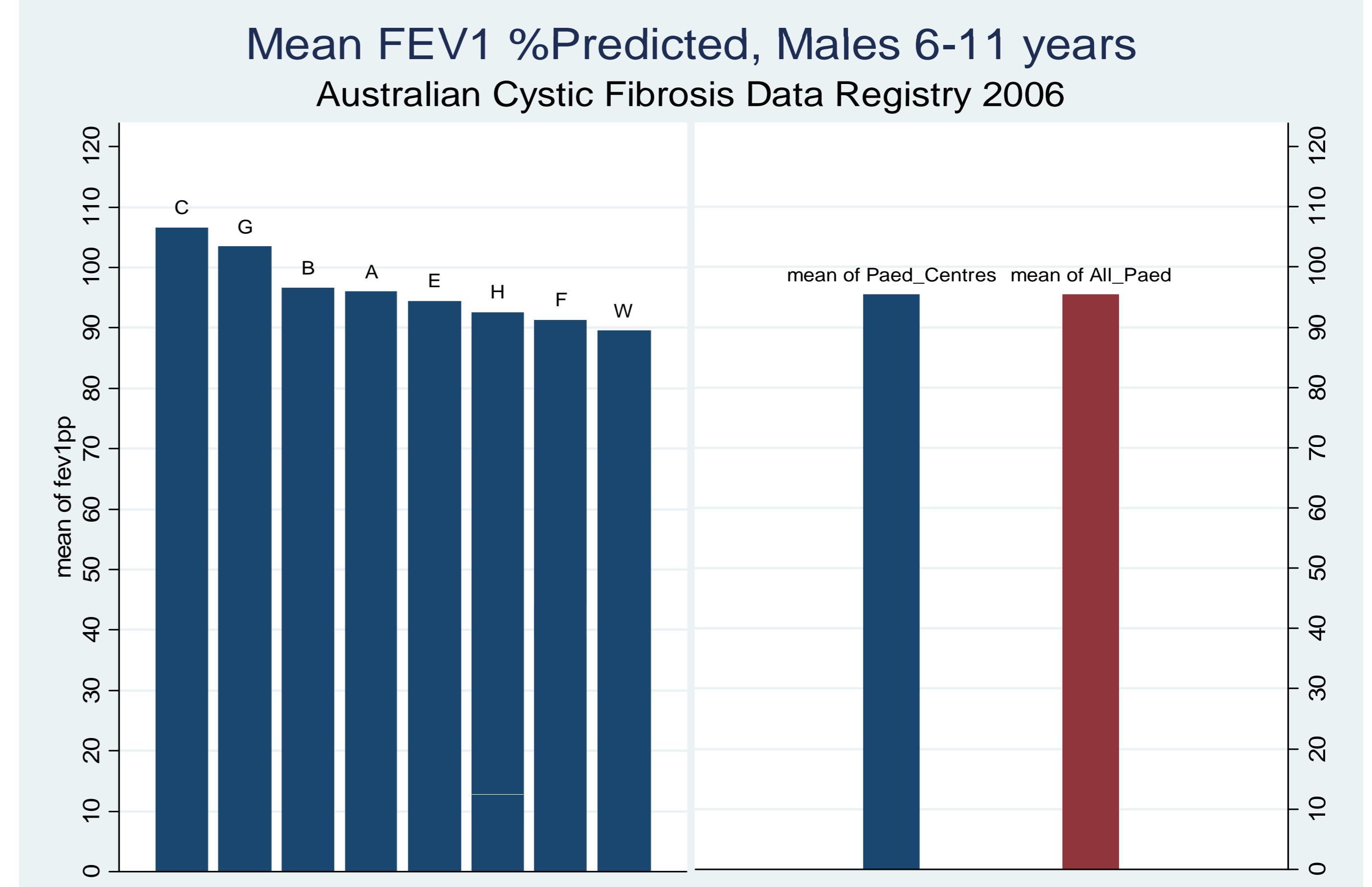
The large, long established patient registry of the United States Cystic Fibrosis Foundation has been used effectively for dissemination of benchmarking indicators, even online via the internet. Many national registries are unable to be as useful to their contributing centres because the number of centres available for comparison is limited in a smaller country. One of the attractions of international centre-based comparisons is that they enable CF clinicians to view outcomes for their patients against a large number of their international peers. The low prevalence of cystic fibrosis places increased value on international studies, relative to other diseases. Regular interaction between CF clinicians provides the opportunity for sharing treatment experiences across national boundaries.

Interim arrangements for sharing a limited range of indicators have been explored between the US and Australian registries. Some results are illustrated in the charts. Informal discussions with registry managers from other countries have revealed wider interest in an multilateral benchmarking of treatment centre patient outcomes across countries.

3. Risk adjustment

Centre level patient outcomes in cystic fibrosis are driven by a number of factors, including case severity, social and other environmental factors. In research studies, multivariate statistical analysis for risk adjustment is common and the technique is being introduced for reporting from some national registries. For international comparisons, this is less feasible. However, stratification of indicators for more homogenous comparisons is a reasonable alternative. From the range of potential covariates, patient age and sex are the most important.

A benchmarking presentation for Australian centre data. The number of centres is small and the opportunity for benchmarking limited.



An example of an international benchmarking presentation: US and Australian centre data with codes identifying Australian centres.

2. Multilateral benchmarking - first steps

Development of standardised indicators is a first step for benchmarking. While harmonising different approaches can be difficult, even at a national level, good outcomes are usually achieved by keeping the objectives simple and limiting the indicators to those of greatest interest.

A scan of research literature and national cystic fibrosis registry reports suggests that it is feasible to identify a short list of indicators that are almost universally used for monitoring patient outcomes. These include, for lung function, FEV1 percent of predicted and, for adult nutrition, body mass index (BMI). Nutritional outcomes for children are reported using a greater variety of indicators, including height, weight and BMI percentiles and corresponding z-scores derived from population-based reference values.

More investigation is needed to compare the methodology for construction of the indicators, such as the choice of reference values. However, even in this respect, recent developments suggest a convergence towards common reference values, at least for lung function. These are matters for further consideration and discussion.

4. Proposed indicators and stratification

The initial indicators proposed for multinational benchmarking are set out in the following table, with suggested age groups. The age dissection reflects the minimum age from which the indicators are usually available and a judgement about the number of groups that can be sustained for robust statistics. Common break points are suggested. While the proposals have a pragmatic basis, there has been some consultation with clinicians. All indicators should be compiled for males and female patients separately.

	Mean values for:		
	FEV1 % predicted	BMI Percentile	BMI (adult)
Age group:			
2 to 5 years		X	
6 to 11 years	X	X	
12 to 17 years	X	X	
18 to 29 years	X		X
30 years and over	X		X
All adults (18 +)	X		X

5. Governance issues

Issues relevant to national level benchmarking are not always simple, but can be resolved under governance arrangements for individual patient registries. Bilateral arrangements between national registries can take such issues into account in formulating information sharing agreements. However, embarking on multilateral benchmarking via multiple bilateral arrangements may have unintended consequences.

6. A way forward?

The time seems right to engage interested parties in more formal processes for managing multi-national benchmarking of patient outcome indicators. Clinical and technical input is required for decisions about indicator specifications and risk adjustment. Some simple proposals have been presented here, to facilitate first steps. But, as the model for governance of many national registries demonstrates, consideration should be given also to engaging a trusted third party custodian, to manage benchmarking data in accordance with rules to be established.

References:

Wiedenmann G, Steinkamp B, Sens B, Stern M for the German Cystic Fibrosis Quality Assurance Group (2001) *The German cystic fibrosis quality assurance project: clinical features in children and adults*. Eur Respir J, 17:1187-1194.

Gawande A (2004) *The Bell Curve: What happens when patients find out how good their doctors really are?* The New Yorker, December 8 2004

Schechter MS and Margolis (2005) *Improving subspecialty healthcare: lessons from cystic fibrosis*. J Paediatr, 147: 295-30.

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