



## Newsletter from the Association for European Paediatric Cardiology

### The European Paediatric Cardiac Code: where do we stand?

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**W**ITH THE PUBLICATION OF THE FIRST revision of the European Paediatric Cardiac Code as a supplement of *Cardiology in the Young* in October 2002,<sup>1</sup> we have realized another important step in our attempts to create a universally acceptable system.

As you remember, our Association decided in 1996 to create a committee to oversee the development of a common European diagnostic and therapeutic code, with the committee convened in particular to include representatives of the paediatric cardiac surgical community.<sup>2,3</sup> At the Annual Meeting of the Association held in Sofia in 1999, the Council and the General Assembly accepted the proposals put forward by this committee. This resulted in the publication of the initial code as a short and a long list.<sup>4,5</sup> At the same time, the codes were made available on the website of the Association ([www.aepc.org](http://www.aepc.org)).

Over the subsequent two years, the code became increasingly accepted and used, not only in Europe, but also in other parts of the world. The coding committee continued to work to improve the code, incorporating suggestions and corrections coming from individual users, as well as those generated from the Working Groups of the Association and from Working Group 22, that concerned with grown-up congenital heart disease, of the European Society of Cardiology. All this resulted in the first revision of the code, which was proposed by the coding committee and approved by the Council and the General Assembly of the Association at the Annual Meeting in Porto in May 2002. This revision has now been published as a further supplement of *Cardiology in the Young*, in October 2002.<sup>1</sup>

The Association, therefore, now has an updated and improved system for coding, of which it continues to have all legal rights as before. The revised code can now be downloaded from our website for non-profit use under the condition of full acknowledgement and acceptance of the rights of the Association. A German

translation of the revised short list will be available on the same website by the end of 2002, and translations into other languages will hopefully follow. Thus, we have now created the basis for a further increase in the use of the code. We know that, already, over 50 centres of paediatric cardiology are working with the code. The short list is now used as the basis for collection of data nationally in Germany and Switzerland, will be used for this purpose by the United Kingdom Central Cardiac Audit Database from April 2003 on. Similar use is planned in the Netherlands and in Belgium.

Besides providing these improvements of the code itself, the coding committee has also worked on developing the necessary cross-mapping to other codes. The cross-mapping to the 9th and 10th revisions of the International Codes of Diseases was already a part of the first publication in 2000. This has now been revised together with the code. As many hospital administrations and governments continue to demand reports based on the International codes, this cross-mapping remains very important, avoiding the need for additional coding.

New in this first revision,<sup>1</sup> however, is a cross-map of the short list of our code to the short list of the code developed by the Congenital Heart Surgery Nomenclature and Database Project, this being a joint venture between the Society of Thoracic Surgeons, the European Association for Cardiothoracic Surgery, and the European Congenital Heart Surgeons Foundation.<sup>6</sup> At present, we have prepared a complete cross-mapping between the short lists. So as to achieve such complete cross-mapping, we enlarged our short list by around 300 items, mainly in the field of surgical procedures. This now permits paediatric and congenital cardiac surgeons to use the comprehensive short list of the European Paediatric Cardiac Code for collating all details of their patients, and at the same time, without additional effort, joining in the important

collection of data for the projects sponsored by the Society of Thoracic Surgeons and the European Association for Cardiothoracic Surgery.

In the supplement, we published also the cross-mapping in opposite direction from the short list of surgical societies to our short list. But, because the surgical short list is not aimed at providing comprehensive coding of any given patient, as explained in detail in one of the explanatory articles in the supplement,<sup>1</sup> this reversed cross-mapping is incomplete. At present, we discourage its use by those employing the European Paediatric Cardiac Code.

Use of the European code, in its current state, therefore, combined with the possibility of cross-mapping not only to the 9th and 10th revision of the International codes, but also to the short list of surgical code, offers the opportunity of joint adventures of cardiac surgeons and cardiologists, such as involvement in programmes for assurance of quality. The experience from Germany has already shown the advantage of creating such a program before it is imposed by the government. As mentioned before, surgeons can now collaborate in such a program without losing the option to participate, at the same time, in the programmes being developed jointly between the Society of Thoracic Surgeons and the European Association for Cardiothoracic Surgery. Since the short list of our own code was elaborated from the outset with the input from the surgical representatives on our committee, and as the revised version brings significant improvements when viewed from the surgical aspects, it is now advantageous for cardiac surgeons to use the European code in the first instance, and to enter the surgical programmes through the cross-mapping. Paediatric cardiologists, and cardiologists involved with congenital heart disease in adults, who are hopefully already using the European code, should now inform all their surgical colleagues of the new advances. It seems to be the right moment now for such a step.

In a long run, we are all striving to develop an international coding system that will be accepted throughout the World. In this regard, the ongoing work of the International Nomenclature Committee for Paediatric and Congenital Heart Disease is very important, and our association takes a very active part

in this group. The cross-mapping of the short lists of the European and surgical codes certainly represents an important step towards this ultimate aim.

At the present moment, nonetheless, the International coding system remains a remote aim. Within our Association, we can now go to work with the revised European code, this first revision certainly offering a clear improvement on the original version. For that, we have to thank Rodney Franklin, who has again put a tremendous amount of work and time into this revision. Our thanks also go to Bob Anderson and the publishers of *Cardiology in the Young*, especially to Gavin Jamieson, for their help and effort in publishing the revised code and the cross-mappings together with explanatory articles. We also acknowledge with thanks the financial sponsors of the supplement, namely the St. Jude Medical company of the Netherlands. Concerning the cross-mapping with the surgical short list, we owe our additional gratitude to the members of the Executive of the International Working Group for Mapping and Coding of Nomenclature for Paediatric and Congenital Heart Disease, namely Marie Béland, Rodney Franklin, Jeff Jacobs, and Christo Tchervenkov. Our coding committee itself will continue its work, from January 2003, under a new chairman. This is Bert Ulmer, to whom all questions and suggestions concerning the code should now be directed. His e-mail address is: Herbert\_Ulmer@med.uni-heidelberg.de.

## References

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