



WORLD HEALTH ORGANIZATION

WHO/HST/ICD/C/97.39  
Distr.: LIMITED  
ENGLISH ONLY

MEETING OF HEADS OF WHO COLLABORATING CENTRES  
FOR THE CLASSIFICATION OF DISEASES

Copenhagen, Denmark  
14-20 October, 1997

**WHO Long-term Strategy for the Development and Management  
of Health-Related Classifications**

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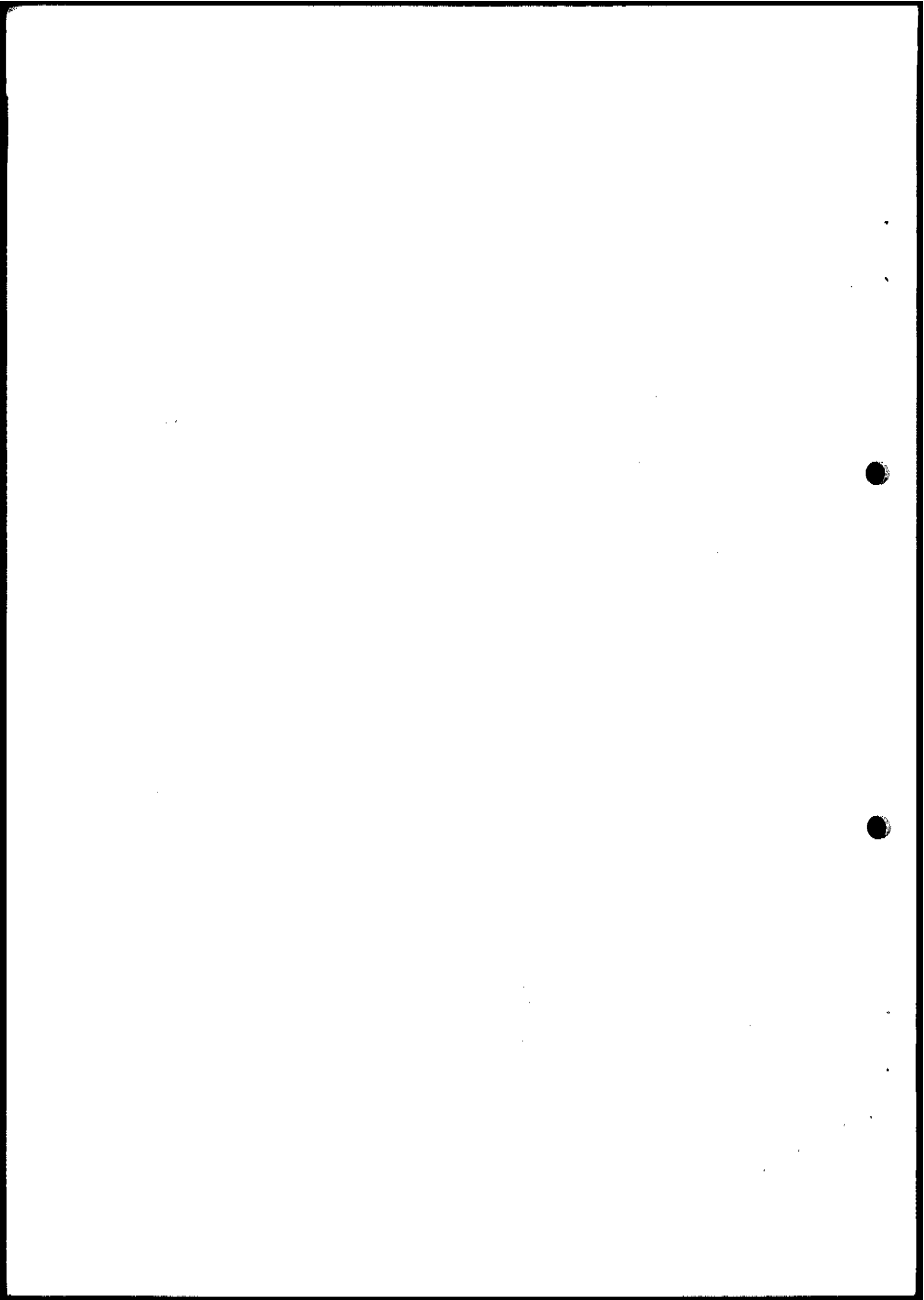
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## WHO Long-term Strategy for the Development and Management of Health-Related Classifications

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## WHO Long-term Strategy for the Development and Management of Health-Related Classifications

### EXECUTIVE SUMMARY

In the introduction to this document, the history of the ICD is briefly reviewed and the basis for WHO's responsibilities in maintaining and updating the ICD, as provided in the WHO Constitution, is noted. The objectives of the long-term strategy are to assist WHO to identify changing needs for the ICD and the Organization's ability to respond to them into the 21st Century. The plan builds on recommendations of the 1989 International Revision Conference, the Forty-third World Health Assembly in 1990, annual meetings of Heads of WHO Collaborating Centres for the Classification of Diseases, and the expressed needs of Member States and other users of the ICD.

In a review of current status, the growth of the use of the ICD for a variety of purposes and the growing use of information technology, including the Internet, are described in relation to changing resources at WHO and their impact on traditional ICD-support mechanisms. The importance of the ICD to HST and other WHO programmes as well as to national health information systems is addressed.

A number of strategic issues affecting the long-term strategy are identified, including:

- the nature and role of the family of classifications surrounding the ICD three-character core;
- the future of the core classification (including its updating) and of its immediate derivatives;
- the tools which support and enhance the quality and utility of ICD data;
- evaluation of interim updates to the ICD and of the tools (including an enhanced role for the Collaborating Centres);
- the role of a variety of forms of electronic dissemination of the ICD and related materials;
- the role of WHO Regional Offices in support of ICD use;
- enhancing the effectiveness of meetings of Heads of WHO Collaborating Centres; and
- HST staff enhancement and development.

The document proposes a plan of action for ICD activities through the year 2010 consisting of several components which address the strategic issues and include:

- affirmation of the parameters for inclusion in the family of classifications and adoption of guidelines for prioritizing work on family members;
- formalization of the updating mechanism for ICD-10;
- evaluation of the updating process with recommendations regarding the future formal revision process;
- review and evaluation of the tools in support of the ICD;
- finalization of the three-character version of ICD-10;
- enhancement of external networks related to automation and classifications other than ICD;
- an internal review of pricing and distribution activities in view of electronic dissemination;
- investigation of the possible return of funds from ICD-related sales to support technical development;
- establishment of minimum ongoing staffing to support permanent ICD-related functions plus an enhancement, at least in the shorter-term, to support commitments made through December 1999;
- provision of informatics support to take advantage of new technologies;
- development of a staff succession plan to support ICD-related responsibilities within HST;
- enhanced WHO Regional Office involvement in support of Member States adoption and utilization of the ICD; and
- improved efficiency and effectiveness of the Centre Heads meetings.

Many of the items in the plan of action require further discussion between HST and the WHO Collaborating Centres for the Classification of Diseases and between HST and other areas within WHO before the strategy can be acted upon by WHO senior management. There is also a requirement for the commitment of additional WHO resources (both human and financial) to support and enhance its classification activities which are the foundation for much of its work and are critical to the development and enhancement of health information systems at the national, regional, and international levels.

## I. INTRODUCTION

### A. Background

The International Classification of Diseases (ICD) is a statistical classification used for the quantitative study of illness, related morbid conditions, and death. The importance of such a systematic classification was recognized as early as the 17th century in the work of John Graunt in the analyses of the London Bills of Mortality and in the early 18th century in the classifications of de Lacroix (Sauvages), Linnæus, and Cullen. However, the present form of the ICD can best be traced stemming from the work of William Farr who became the first medical statistician of the newly-established General Register Office of England and Wales in 1837. Farr proposed principles for a uniform statistical classification of mortality that have, in many instances, persisted to this day in spite of the several changes in governance and in form which have subsequently taken place in the classification. The concept of a uniform classification attracted the attention of the International Statistical Congress and its successor, the International Statistical Institute, under whose ægis the classification evolved based on work by Farr, d'Espine, Bertillon, and others. Over time, the responsibility for the development, maintenance, and improvement of the ICD passed from the International Statistical Congress and the International Statistical Institute (ISI) to a Mixed Commission comprised of representatives of the ISI and the Health Organization of the League of Nations, and finally to the World Health Organization.

The basis for WHO's responsibilities for the ICD and related health classifications can be found in the Organization's Constitution. Chapter II, Article 2 lists, *inter alia*, the following subparagraph functions<sup>1</sup>:

- c) to assist Governments, upon request, in strengthening health services;
- f) to establish and maintain such administrative and technical services as may be required, including epidemiological and statistical services;
- q) to provide information, counsel, and assistance in the field of health;
- s) to establish and revise as necessary international nomenclatures of diseases, of causes of death, and of public health practices.

### B. Objectives

In view of WHO's constitutionally-mandated functional responsibilities to the support of health statistical services including the development and maintenance of relevant statistical classifications and their use, this long-term strategy is developed to assist in the Organization's distribution of scarce resources to carry out those ICD activities necessary for the fulfillment of health statistical objectives, both of the Organization itself and of Member countries. *The*

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<sup>1</sup>*Basic Documents, Forty-first Edition*, Geneva, World Health Organization, 1996, pp 2-3.

*International Statistical Classification of Diseases and Related Health Problems* is virtually universal in its acceptance as a standard statistical tool, essential at the international, national and local levels for the quantification of mortality, morbidity, and related health problems. The classification is at a threshold as the 21st century approaches; new demands for information, and new technologies for capturing, storing, retrieving, and disseminating information suggest this as an appropriate moment in the "life" of the ICD to step back and take a fresh look at the process of developing, maintaining and supporting it. This plan will assist in the identification of changing needs and WHO's ability to respond to them.

### C. Approach

The plan will build on the recommendations of the International Revision Conference<sup>2</sup>, the decisions of the Forty-third World Health Assembly in 1990, discussions at recent annual Heads of Collaborating Centres meetings<sup>3</sup>, Secretariat evaluations of the status of various current and ongoing ICD-related tasks, and the requirements of Member States and other users of the classifications.

## II. REVIEW OF CURRENT STATUS

As noted in the introduction to ICD-10<sup>4</sup>, the ICD has had an impressive history of development. While early revisions had been concerned only with causes of death, the scope of the classification had been extended at the Sixth Revision in 1948 to include non-fatal diseases. This extension has continued through the current version. In addition, there have been publications, on a trial basis, of supplementary classifications of procedures in medicine and of impairments, disabilities, and handicaps. Recognizing the expanding uses of the ICD, it was realized during the preparation of the Ninth Revision that the ICD alone could not cover all of the needed health information and that a more practical concept might envisage a "family" of disease and health-related classifications to address different public health requirements, using the ICD at the three-character level as the central, or core, classification.

On a world-wide basis, there has been a growth of uses for the ICD, spreading from the original need to classify causes of death on to indexing and retrieval of hospital records, to

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<sup>2</sup>*International Statistical Classification of Diseases and Related Health Problems, Tenth Revision*, Volume 1. Geneva, World Health Organization, 1992, pp. 11- 28.

<sup>3</sup>*c.f.* Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases, Tokyo, Japan, 15-21 October 1996. Unpublished document WHO/HST/ICD/C/96.54. Geneva, World Health Organization, 1997.

<sup>4</sup>*International Statistical Classification of Diseases and Related Health Problems, Tenth Revision*, Volume 1. Geneva, World Health Organization, 1992, p. 11.

hospital and general morbidity studies, as well as a rapidly emerging need for additional classifications needing coordination and compatibility with the ICD, such as the aforementioned classifications of procedures in medicine and of impairments, disabilities, and handicaps. The infrastructure for supporting these additional applications has not kept pace with the demands nor has there been sufficient accommodation made for the increased diversity and complexity of the day-to-day work brought about by technological advances such as electronic dissemination of products on diskette, CD-ROM, and on the Internet as well as applications of ICD computer-based training. In fact, resource constraints and other emerging health priorities have necessitated reductions in the WHO staffing levels for this activity. While there are many complex reasons for this to have happened, it is nevertheless a fact that ICD-related work was supported from the period 1948 to the early 1980's by a staff of eight, while today this staff consists of fewer than two full-time equivalents. During that same period, the number of WHO Collaborating Centres for the Classification of Diseases has grown from the original centre in London to additional centres in Paris, Caracas and Moscow and then further expansion to Washington, São Paulo, Beijing, the Nordic countries, Canberra, and Kuwait; along with the Office of the ICD, Japan and the Dutch National Committee for the Standardization of Informatics in Health Care (CSIZ) as regular participants at annual meetings. While it is correct that the expanded number of centres is a resource to WHO, especially in support of language or country specific applications of the ICD, it is also true that the expansion of centres has resulted in additional burdens for WHO staff through heightened ICD awareness in Member countries with concomitant increases in new applications and expanded uses. For example, there are now approximately thirty-three national versions in use in addition to the English and French versions which are the responsibility of WHO Headquarters. Additionally, there has been an exponential increase in the use of the ICD for morbidity purposes, especially in French-speaking countries.

While it is difficult in retrospect to evaluate the need for a staff of as many as eight persons in the former ICD unit in the earlier years, it is not so difficult to see that the current level of staffing is not adequate for the tasks. If some of the funds realized by the Organization from the personnel reductions had been left with the program, it might have been possible for adequate amounts of alternative support to have been obtained through contractual services or other external sources of expertise, but this, too, is difficult to assess after the fact.

It is, however, possible to identify currently essential ICD-related activities (Annex 1), determine how, where, and when these should be carried out, and to prioritize them. On this basis, human and fiscal requirements can be estimated and a long-term strategy can be developed to rationalize programmatic needs with resource allocations.

It has been previously indicated that the antecedents to the present ICD were entrusted to WHO at its establishment and embodied in the WHO Constitution as a functional responsibility. However, that does not imply any greater or lesser importance for the ICD than other constitutional functions. Clearly, ICD activities must remain relevant to the overall strategies of the Organization and be an integral part of the Headquarters programme. The ICD and other

health-related classifications (i.e., the Family of Classifications) are an essential component of the Health Situation and Trend Assessment Programme which has responsibility for global health situation analysis and projection, strengthening of country health information (including health information systems which incorporate the ICD) and partnerships and coordination of epidemiology, statistics, and trend assessment. These classifications and the HST mortality database also contribute to global epidemiological surveillance, a function of the Emerging and other Communicable Diseases Surveillance and Control Programme. The ICD-based information also supports other technical programmes at WHO Headquarters and Regional Offices such as the Expanded Programme on Immunization; Health and Environment; Information System Management; the Special Programme of Research, Development and Research Training in Human Reproduction; and the Special Programme for Research and Training in Tropical Diseases. Epidemiological and statistical analyses, many of them heavily dependent on data related to causes of death, injuries, and illnesses derived from the ICD, contribute significantly to the formulation of the WHO health-for-all policy and strategy for the next century.

### III. STRATEGIC ISSUES

#### A. The Family of Classifications

In order to consider ICD-related activities that are relevant to current and future international and national needs, it is first necessary to define the family of classifications that should be included in the scope of work of WHO and of the Collaborating Centres. The concept of a family of classifications was originally seen as a dynamic group of health-related statistical classifications based on the core ICD, dependent on definitions or statistical practices inherent to the ICD, or linked in some other fashion to the ICD. While this was a useful concept to establish WHO interest, involvement, and, in some instances, control of many health and health-related classifications, an amorphous and changing web of classifications requiring WHO involvement does not lend itself to assessment and planning for future WHO activities. Therefore, as an essential step in the development of a long-range plan, criteria for inclusion of a classification into the family and an explicit statement of WHO responsibilities for each class of "family" membership<sup>5</sup> is required. Centre Heads have previously provided some criteria for family membership<sup>5</sup>. They proposed that a classification can be accepted into the family of disease and health-related classifications when:

- it is supported/requested by a large number of Member States and/or an authoritative international organization
- it is of importance to WHO activities

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<sup>5</sup>Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases, São Paulo, Brazil, 9-15 April 1991. Unpublished document SES/ICD/C/91.26. Geneva, World Health Organization, 1991.

- it is not in conflict with the ICD or other classifications in the family

Subsequently, Centre Heads have discussed additional criteria such as ease of use, validity, and quality of input data but these additional criteria have not been formally proposed or adopted.

The general scheme (Annex 2) classifies disease and health-related classifications into five groups:

1. ICD three-character core classification and direct derivatives (i.e. ICD four-character classification, and short tabulation lists)
2. Specialty-based adaptations.
3. Information support to primary health care
4. Other health-related classifications
5. International Nomenclature of Diseases

Since all ICD-related activities stem from the core classification, each of the other family group's degree of relationship to the core classification should be one of the primary determinants of the required level of WHO/HST involvement and/or support.

*Specialty-based adaptations*- Specialty-based adaptations draw directly upon the existing three- and four-character structure of the ICD, but more detail is often given by means of fifth- or sometimes sixth-character subdivisions. Speciality-relevant sections or categories which may have been scattered throughout the ICD are usually brought together in one compact volume. Appropriate definitions, a glossary of terms, and an index are frequently part of such an adaptation.

*Information support to primary health care*- Definitions and methods of data collection and analyses at the local level in support of primary health care, including lay reporting and other community-based health information schemes have been closely linked to the ICD but are not directly linked to or derived from it.

*Other health-related classifications* - These classifications typically include health problems, impairments, disabilities, handicaps, reasons for encounter with the health care system, and medical and surgical procedures. While not directly based on the ICD, these classifications often link with an ICD code if a diagnosis is related to the matters being classified.

*International Nomenclature of Diseases* - This is a multi-volume publication<sup>6</sup> which is related to, but not derived from, the ICD. The ICD is a statistical classification which groups similar

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<sup>6</sup>*International Nomenclature of Diseases*. Geneva, Council for International Organizations of Medical Sciences and World Health Organization, multiple volumes, various years.

conditions into mutually-exclusive categories in a hierarchical fashion, while a medical nomenclature is an exhaustive set of titles comprised of each known morbid condition. The concepts of classification and nomenclature are closely related because a nomenclature is often arranged systematically and also serves as a primary source for the vocabulary used in a statistical classification.

Guidelines are proposed (see Section IV.A ) for determining the level of WHO/HST effort with regard to the Family of Classifications. However, it should be recognized that newly proposed classifications or changing circumstances might require deviations from the guidelines after appropriate consideration and decision by the Director, Division of Health Situation and Trend Assessment (HST).

At the time of the International Conference for the Tenth Revision of the ICD, it was recognized that specialty-based adaptations of the ICD and health-related classifications would likely become numerous in the future and the recommended role of WHO as a clearing-house for information about these classifications was considered to be extremely important. This is seen to be particularly true with respect to facilitating the dissemination of information about national (language) initiatives.

## **B. The Future of the Core Classification and Its Immediate Derivatives**

1. Following the recommendation at the International Conference for the Tenth Revision of the ICD for an updating process, there have been discussions on this topic at successive meetings of the Heads of WHO Collaborating Centres for the Classification of Diseases. There has been agreement on some aspects of the updating mechanism for ICD-10, such as the time lines for submission, evaluation, and agreement. Various methods of dissemination have also been addressed. As can be seen in Annex 3, discussions at the Centre Head meetings have also identified a range of types of updates that might be requested. For the first time, some proposed updates were officially discussed at the 1996 Centre Head meeting. To date, however, the only changes that have been approved have consisted of changes to the index proposed by the Secretariat.

A formal mechanism for processing, accepting, and promulgating ICD-10 updates has, in fact, not yet been adopted. As part of the plan of action in a later portion of this document, some suggestions are provided for consideration.

2. It has been previously indicated that, within the family of classifications, the ICD three-character core classification and its immediate derivatives should receive the highest priority. However, the classification, and the ways in which it is distributed, maintained, and revised are in transition. Its uses and applications are also changing at an accelerated pace. It is no longer appropriate to use the same mechanisms of support as have been used since the inception of the classification over one hundred years ago. This plan will not, therefore, assume that the

classification will remain essentially static during a given "revision cycle" of, say, ten or fifteen years. Rather, it is assumed that an updating mechanism, annually implemented, will keep the ICD relatively up-to-date and error-free. The updating mechanism which will introduce necessary changes while resisting pressure for highly parochial or trivial modifications and which will allow efficient dissemination of the updated material is a challenge that must be given immediate, high priority attention. This includes careful examination of statistical as well as classification issues. In addition, it is assumed that printed versions of the ICD will become less important and that the medium of choice for distribution of the classification and its associated products will be electronic. Because of these assumptions, a large body of prior experience in dealing with ICD matters and their associated timetable probably will no longer be applicable. On the other hand, new approaches will hopefully bring efficiencies and improved timeliness of products - but there will be a cost as well to bring the ICD and related health classifications into the 21st century.

3. In association with the core classification and its immediate derivatives, there is a set of closely related tools which support and enhance the quality and utility of ICD data. These include items such as:

- (a) conversion tables;
- (b) bridge coding exercises and comparability ratios;
- (c) training (e.g., TENDON);
- (d) automated encoding and coding-assisting software (e.g., MICAR, LUCID);
- (e) data presentation (e.g., tabulation lists);
- (f) analytical methods (e.g., multiple cause of death analysis).

When planning core classification activities, these and similar tools which support the use and interpretation of the classification should be given similar priority as the work on the basic classification itself. However, the actual tasks may be appropriate for development by one or more of the Collaborating Centres with coordination by HST, rather than all being undertaken centrally. (see also Section III.C.3)

### **C. Other Key Issues to be Addressed as Part of a Long-term Strategy**

1. The time period to be covered by this plan is assumed to be, as a minimum, from the date of acceptance of the plan through the year 2010. This period of time will encompass the dates when key ICD events might occur if no major changes in schedule and approach are made. By including these dates within the planning period, the impact of any proposed changes can be evaluated. On the other hand, too long a period might require significant "mid-course" corrections resulting from uncertainties and changes in the longer range future while too short a period would not permit appropriate advanced planning.

2. The most important step in a long-term strategy is the early evaluation of a full implementation of the concept of interim updates to the ICD. All aspects of this process have not

yet been explored, and the complexities of keeping all interrelated parts of the Family of Classifications in synchrony is an issue to be examined. Yet, the decisions related to a possible ICD-11 are contingent on the success or failure of the updating process. All timetables of work and resource allocations during the next five to 10 years are dependent on the evaluation of this mechanism. The International Conference for the Tenth Revision of the International Classification of Diseases recommended an updating mechanism, and also recommended that the next revision conference be held in 1999. These recommendations were approved by the Forty-third World Health Assembly. Based on the Assembly's endorsement of the Revision Conference's actions, an ICD-11 revision would come into force in 2003. Clearly, this does not appear reasonable if the traditional approach is followed, but not enough is yet known to determine if interim updates will obviate the need for a revision *per se* rather than a reprinting incorporating the modifications which had been approved up to that point.

3. The tools supporting the use and interpretation of the core classification and its immediate derivatives (Section III.B.3) should be evaluated and, where appropriate, advance plans drawn up to keep them in synchronization with changes in the classification(s) and with technological and methodological advances. Most, if not all, of the developmental work for these tools lends itself to decentralization to Collaborating Centres or other appropriate institutions, requiring for the most part only coordination from WHO. If undertaken on a voluntary basis but with sufficient advance notice, the Collaborating Centres can make significant contributions while providing important support to Headquarters. At the same time, such activities strengthen the capabilities of the Centres and assist them in their own staff development.

4. An important consideration for WHO health-related classifications for the immediate and longer range future is the medium on which the classifications and related material are distributed. Electronic versions, in the form of floppy disks and CD-ROMs, are already in use and are often the preferred medium rather than paper-based products. These forms of storage of information or similar but technologically-improved storage media will probably continue to replace the use of paper versions of information. However, distribution on media of these types is relatively easily controlled by WHO for purposes of copyright protection and for revenue-producing sales. Just as with printed products, the Organization can establish policies regarding free distribution of items, reduced pricing for, say, developing countries, pricing for other Member countries, and pricing for non-governmental or commercial uses. It can negotiate terms for uses which incorporate the classification(s) into software or other proprietary data systems as part of the copyright protections. At the same time, recognition must be given to the fact that the development of WHO's health-related classifications often is partially dependent on technical and resource support of some Member governments, NGOs, and other outside agencies and organizations. Accordingly a clear statement of pricing policy for electronic products should be rationalized and publicized as part of the overall strategy for the ICD. This policy should make allowance for the fact that the ICD is an international standard and required for specified applications in the same way as the metre or gramme are international standards for measurement of length and weight.

5. Another essential consideration for WHO health-related classifications for the immediate and longer range future is access to electronic products either for viewing or for downloading from the Internet. The Internet has become a common and convenient vehicle for the rapid sharing and transfer of information on a world-wide basis. Many ICD products lend themselves well to this process as part of the goal of widespread dissemination and use of the classification and publication on the Internet not only promotes this dissemination and use but also provides an avenue to make updates, clarifications, interpretations, etc. available to users on a timely and efficient basis. Therefore, Internet publication seems like a highly desirable objective, but equitable access policies must be developed first.

To protect the copyright and to address revenue concerns, Internet availability of the ICD should not result in a way to get around the pricing schedules and policies for printed or electronic media items. This suggests that Internet availability should be based on password access for those previously given authorized access, password access for those who pay an appropriate fee while on line (e.g., by payment via credit card - a common practice for many other Internet services), or free for those materials and demonstrations that should not be associated with a fee (such as, say, errata, updates, and descriptive material.) Therefore, the long-term strategy must address these issues from the points of view of efficient distribution of information to users, equitable pricing policies and copyright protection, and WHO revenues for future support of ICD-related activities.

6. Once a new revision of the ICD and the associated tools have been developed, one of the roles of WHO is to facilitate and/or assist with the ICD implementation among existing ICD users. Another role is to expand the use of the classification to additional countries and/or from mortality application only to both mortality and morbidity applications. These roles do not rest with HST alone but rather rest, to a large extent, with the WHO Regional Offices. Some of these offices deal with a large number of countries and may also deal with a wide variety of national languages (for many of which there are no Collaborating Centres). A few of the Regional Offices have established an internal level of competency in this regard while others have established a roster of individuals who can be brought in to assist them on a periodic basis. Other offices have, in the past, relied on resources from HST and the Collaborating Centres. As the quantity of classification expertise available at HST has diminished and the resources available through or from the various Collaborating Centres for the classification of diseases may also be limited, the Regional Offices who have not built up their own bases of expertise may have difficulty fulfilling these roles.

The ICD is only one component of a national health information system and, with the increasing technical complexity of both the classification itself and the informatics support to health information systems, a coordinated, team approach to providing assistance to countries has become necessary. Such an approach necessarily involves several areas within WHO including the Regional Offices.

7. The meetings of Heads of WHO Collaborating Centres need streamlining, especially in view of the continuing expansion of topics requiring discussion and resolution by Centre Heads. In spite of frequent past agreements on the part of Centre Heads to complete written material by an agreed date, papers continue to be submitted too late for pre-meeting circulation in a timely manner. This unnecessarily prolongs discussions at meetings and may result in inadequate or inappropriate consideration of important items.

In order to maximize use of available meeting time and to allow thorough discussion of important issues, it has been suggested that concurrent "break-out" sessions, each devoted to a key issue, be utilized during Centre Heads meetings. This might result in the exclusion of one or more Centre Heads from discussions of importance to them, especially in the case of Centres represented by just one person. Alternatively, subcommittees charged with the exploration of important issues could prepare background papers and recommendations during the interim between meetings, working preferably by e-mail. By use of this mechanism, a wide range of input from outside experts could also be gathered, which would not be immediately available at meetings. Subcommittee reports could be reviewed by the full group during the meeting. In this way, more efficient use of meeting time would result in wider participation by all attendees at the meeting.

8. There is presently no provision in HST for training of staff to assume ICD responsibilities in the future. When the incumbent Technical Officer leaves his post it will be too late to begin a succession plan. ICD-related skills are not commonly found in the work force, even amongst otherwise highly-trained professionals, and the requisite on-the-job training takes years. In addition to the unique technical skills required for ICD-related work, there is a special need for strong linguistic skills in English and French because of HST's responsibility for ICD support in both of these languages.

Unless the Organization takes steps to prevent it, there will be, in the foreseeable future, a severe loss, not only of nosological and linguistic skills, but also of almost all traces of institutional memory of ICD issues, practices, and processes.

#### **IV. A PLAN OF ACTION FOR ACTIVITIES THROUGH THE YEAR 2010**

##### **A. The Family of Classifications**

1. HST, in consultation with the Centre Heads, should affirm a definition of parameters for inclusion into the family of classifications as proposed in 1991 (see Section III.A.).

2. HST, in consultation with the Centre Heads, should adopt operational guidelines for prioritizing work on health-related classifications.

*Guidelines for prioritizing work on components of the Family of Classifications:*

- Tasks related to the ICD three-character core classification and its immediate derivatives are considered to be "critical" or "highly desirable" and must be given higher priority than any other task involving another member of the family.
- Work on *speciality-based adaptations* must be undertaken by organizations external to HST. The responsible organization must agree in writing to follow HST-specified principles in preparing the speciality classification and any other copyright restrictions imposed by WHO. They must, as part of the principles, agree to WHO review before publication and abide by any WHO objections.
- Priority for approval of HST staff involvement in the development of *speciality-based adaptations* should be given as follows: (1) the work is to be undertaken primarily by another WHO Division or Unit; (2) the work is to be undertaken primarily by an NGO; (3) the work is to be undertaken primarily by an international professional society; (4) the work is to be undertaken primarily by a nationally-recognized professional society; or (5) the work is to be undertaken by any other organization or group whose professional competence is acceptable to WHO. This prioritization carries no implication of descending levels of competence; rather, it is a reflection of the increasing level of WHO/HST staff support that might be required to produce an internationally acceptable end-product.
- Work on *other health-related classifications* must be undertaken by organizations either external to HST or in collaboration with HST. Any links to the ICD must be in conformity with HST-specified principles in preparing the classification and with any other copyright restrictions imposed by WHO. The responsible organization must, as part of the principles, agree to HST review before publication and to abide by any WHO objections. Work on a procedure classification or framework would fall into this category.
- All work on members of the Family of Classifications must be reported to Heads of WHO Collaborating Centres at least on an annual basis, and Centre Heads should be given the opportunity to furnish advice and to recommend approval prior to final WHO approval. Centre Heads' recommendations should focus on the links with the ICD; other areas of comment should be in the nature of suggestions only.
- *Information support to primary health care* should be on an information-exchange basis with no measurable HST ICD-related resources being involved.

- Communication between the *International Nomenclature of Diseases* and HST should be maintained but little other activity should be required, except, perhaps, at times when the ICD updates or revision is in progress.

Any deviations from these guidelines should be approved by the Director, Division of Health Situation and Trend Assessment (HST) only after consideration is given to programmatic needs within the Organization and input from the Heads of WHO Collaborating Centres has been received and reviewed.

3. Based on its own activities and on information provided by Collaborating Centres (particularly during annual meetings of Heads of Centres), national and international organizations, national governments, and Regional Offices, HST should serve as a clearing-house of information on the Family of Classifications and related activities. Such information might be made more widely available through the use of the Internet (including the publication of the reports of Centre Heads meetings).

#### **B. Formalization of Updating Mechanism**

HST, in consultation with the Centre Heads, should formalize the updating mechanism which was addressed most recently at the Centre Heads meeting in Tokyo in 1995 (see Annex 3).

The updating mechanism for ICD-10 (both the three-character core and four-character versions) must, of course, be coordinated by WHO/HST. Users of the classifications must be encouraged to contribute to this updating and the agreed upon route for such contributions is through the Collaborating Centres. The following are some suggestions for inclusion in the formal updating mechanism:

- There should be widespread communication or publication of the process for submitting requests for change(s) to the ICD-10 (including the contact information for the Collaborating Centres and their areas of responsibility).
- Requests, once received by Collaborating Centres, should be subjected to a preliminary review.
- Once reviewed, requests and all supporting documentation (including the results of the preliminary review) should be disseminated in English (along with the original language materials, if other than English) to HST, all other Collaborating Centres, and to members of the "Updating Reference Group" (see description below) for review.
- A standing international "Updating Reference Group" should be established to provide advice on changes, additions, deletions to the ICD-10. Membership in the group should be by nomination by Centre Heads and HST with periodic rotation. The mix of members

should ensure a wide variety of input related to the use of the classification for data collection and statistical output for both morbidity and mortality. The work of the group should be carried out by e-mail or other electronic means. The number of members of this group should not exceed 20 persons with final approval resting with HST.

- HST, with the assistance of the Updating Reference Group, will evaluate the requests and recommend appropriate action to be taken at the next meeting of the Centre Heads.
- Changes that are accepted at the Centre Heads meeting will be disseminated electronically with a clear indication of their effective date. A revised classification will be made available in English and French on diskette and CD-ROM, with details of the actual changes available via the Internet.
- Changes introduced into the ICD-10 must also be reflected in any associated tools.

In addition to changes to the ICD-10 which require international agreement through the updating mechanism, there may be minor modifications which are introduced in national versions of the classification. Such modifications should be distributed to WHO/HST and to the Collaborating Centres for information.

An issue that must be considered in the updating of ICD-10 is the relationship between the content of the ICD-10 itself and the content of other members of the family of classifications, particularly the specialty adaptations. One phase of the ICD-10 updating mechanism that cannot be overlooked is that of assuring consistency between the family members. Similarly, proposed modifications to family members must be evaluated in terms of the impact on the ICD-10.

### **C. Evaluation of the Updating Process and Future Revisions**

After three years of experience using the formalized updating mechanism (which should be implemented for 1998), an evaluation of the process should be made by WHO and presented to the Centre Heads. Based on the results of the evaluation, HST, with input from Centre Heads, should recommend to the Director-General either:

1. Continuation, with refinements if necessary, of the updating process, with planned reprintings and electronic updates of the ICD based on the previously approved updates. A new CD-ROM version of the classification could be issued annually. The details of the updates would be highlighted on each version of the CD-ROM and on the Internet. The naming convention for the ICD should be modified to show the periodic updates followed by cyclical formal reprintings, perhaps by a designation such as "ICD Tenth Revision, Updated through 1998"; "ICD Tenth Revision, Updated through 1999"; ... ; "ICD Eleventh Revision"; etc. These might be referred to in abbreviated form as "ICD-10, 1998 Edition"; "ICD-10, 1999 Edition"; ... ; "ICD-11"; etc.. This kind of change in process would probably eliminate the need for the traditional Revision

Conference and would require the agreement of Member countries.

or

2. Reverting to the traditional approach of essentially freezing the content of the ICD through some set period of time, soliciting suggestions for change, and producing a new Revision, as in the past. This approach would require the Director-General to solicit approval of Member countries to change the target date for implementation of ICD-11, since the World Health Assembly's target date is no longer feasible.

#### **D. Review and Evaluation of ICD-related Tools**

A review and evaluation of the ICD-related tools (such as those listed in Section III.B.3 above) should be undertaken in collaboration with the Centre Heads. Timetables for these need to be established by HST with input from Centres and voluntary assignments given to appropriate Centres or institutions. Interim reports on work on these tools should be given at annual Heads of Centres meetings.

#### **E. Finalization of Three-character Version**

In order to increase the utility and use of ICD-10 around the world, HST should proceed as quickly as possible with the finalization of the three-character version (in English and French). In addition, HST should investigate the development of basic software which would facilitate morbidity data collection. Such activities would, no doubt, require some additional funds to support the resources necessary for the development work.

#### **F. Enhancement of Classification-related Networks**

HST should develop and maintain contacts with groups working not just on classifications, including members of the family, but on their application especially through various forms of automation. Examples of these are the work on LUCID ("The Ultimate Interactive Codification of Diagnosis") and the various "Galen-in-use" projects such as GRAIL ("GALEN Representation and Integration Language) and SPET ("Surgical Procedure Editing Tool").

#### **G. Review of Pricing Policies and Distribution Activities**

1. HST, in consultation with Centre Heads, should work out with the WHO Division of Publishing, Language and Library Services (PLL) a pricing and distribution plan for current and future ICD materials that would allow, in addition to traditional printed versions, controlled access via the Internet as well as the use of other forms of electronic media for new and updated materials.

2. HST should investigate possible mechanisms for returning funds realized from the sales of ICD-10 and associated products to the technical unit in order to support the ongoing development, and maintenance of the classification and the related tools.

#### **H. Minimum Ongoing Staffing and Resourcing**

There are several levels of support which WHO might choose for the provision of human and fiscal resources for health-related classifications. Obviously, each choice of level carries with it concomitant programmatic implications. The resources needed for each choice and its programme implications must be worked out in detail by HST for presentation to WHO senior management. However, the current status of one Technical Officer and part time secretarial support for ICD-related activities, does not permit WHO to meet expectations of many Member countries and other users.

A **minimum** level of resources to maintain a set of reasonable permanent functions (see Annex 1) would require at least a staff consisting of one full-time technical officer, one full-time support person, and one full-time secretary along with adequate regular budget resources to enable the recruitment of consultants to carry out planned activities during each biennium.

Other specific activities already planned for the period September 1997 - December 1999 (see Annex 4) clearly require enhancements to the minimum support level.

In light of the special linguistic requirements of the ICD work within HST, any replacements or enhancements of staff should be fluent in English and French.

#### **I. Provision of Informatics Support**

The move to the use of technology such as CD-ROM and the Internet has increased the complexity of maintaining the necessary databases, making updates, tracking changes, etc. Such maintenance must be carried out with direction and coordination from subject matter experts in HST. In addition, however, dedicated informatics resources are necessary. These must be provided by the WHO Division of Information System Management (ISM) or funds must be made available to purchase such services.

#### **J. Succession Planning**

WHO should develop a succession plan in order to train new staff to assume ICD responsibilities when the inevitable replacement of the present incumbent becomes necessary. This may be accomplished by on-the-job experience to be gained by support staff working under the guidance of the incumbent Technical Officer.

#### **K. WHO Regional Office Involvement**

WHO Regional Offices which do not already have expertise in the area of classification should establish a pool of such expertise, either within their staff or through the development of a pool of external resources that may be contracted periodically (including persons employed in national ministries or agencies). The expertise should encompass a broad knowledge of the ICD and the associated tools, the ability to develop and deliver training, and the ability to assist with development and implementation of associated data collection systems. While ICD-related tools such as materials and software may be available from HST, the human resources should be the responsibility of the Regional Offices. With such expertise in place, Regional Offices will be better positioned to contribute to the ongoing maintenance of the classification based on the needs of countries within their region.

While knowledge of the ICD itself requires specific technical expertise, there are additional needs such as statistical knowledge and informatics knowledge which may be necessary to provide the most appropriate assistance to countries. This cannot be expected to be provided by an individual. Instead, Regional Offices must be positioned to provide a coordinated, team approach to ensure ICD implementation as part of an overall health information system.

#### **L. Governance and Functioning of Centre Head Meetings**

Centre Heads should review and either reaffirm or modify previously agreed actions regarding the terms of reference and functioning of Centre Heads Meetings (Annex 5).<sup>7,8,9</sup> A procedure for subcommittee work between meetings should be established so that thorough exploration and recommendations regarding important topics can be given ample time for preparation, circulation prior to meetings, and can be efficiently discussed and resolved by all parties at meetings.

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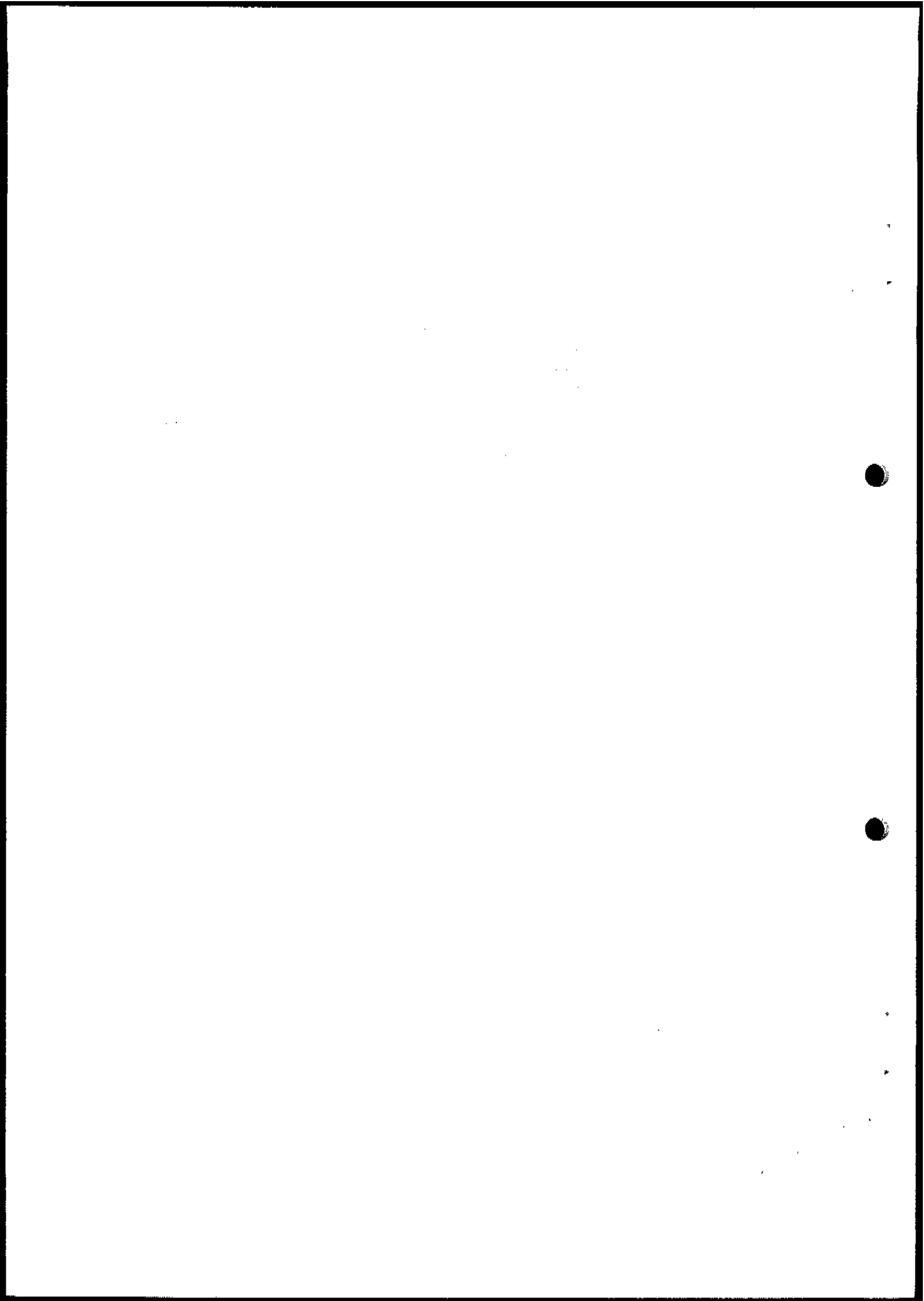
<sup>7</sup>Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases, London, UK, 27 March-2 April 1990. Unpublished document DES/ICD/C/90.27. Geneva, World Health Organization, 1990.

<sup>8</sup>Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases, São Paulo, Brazil, 9-15 April 1991. Unpublished document SES/ICD/C/91.26. Geneva, World Health Organization, 1991.

<sup>9</sup>Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases, Canberra, Australia, 10-16 October 1995. Unpublished document ESS/ICD/C/95.48. Geneva, World Health Organization, 1995.

## V. CONCLUSION

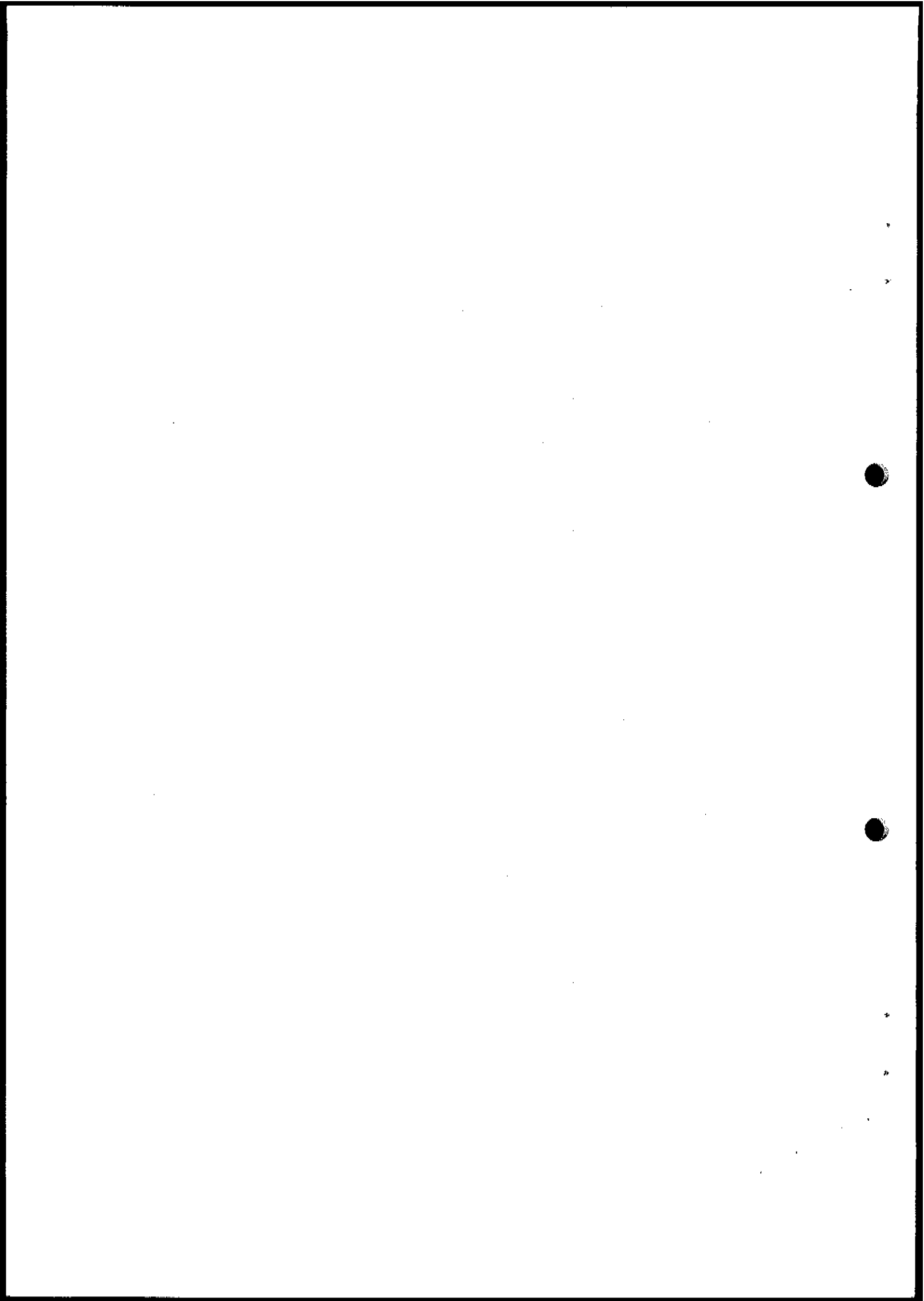
This document has attempted to highlight the importance of the ICD and associated classifications and tools both to WHO and to Member States. A number of strategic issues which pertain to the development and management of the ICD itself and to other health-related classifications are identified. A plan of action for the next decade or so is proposed. Many of the items in the plan of action require further discussion between HST and the WHO Collaborating Centres for the Classification of Diseases and between HST and other areas within WHO before the strategy can be acted upon by WHO senior management. There is also a requirement for the commitment of additional WHO resources (both human and financial) to support and enhance the Organization's classification activities. These activities and their results are the foundation for much of the Organization's work and are critical to the development and enhancement of health information systems at the national, regional, and international levels.



**WHO Long-term Strategy for the Development and Management  
of Health-Related Classifications**

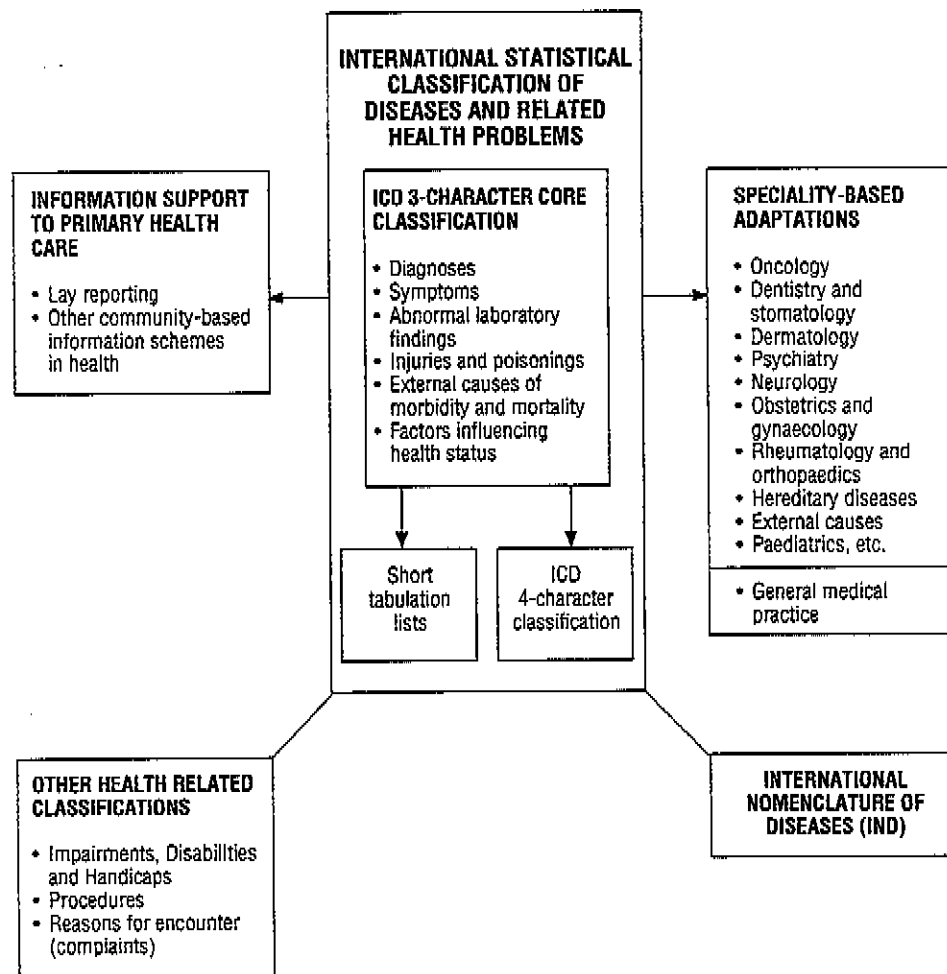
**PERMANENT ICD-RELATED FUNCTIONS**

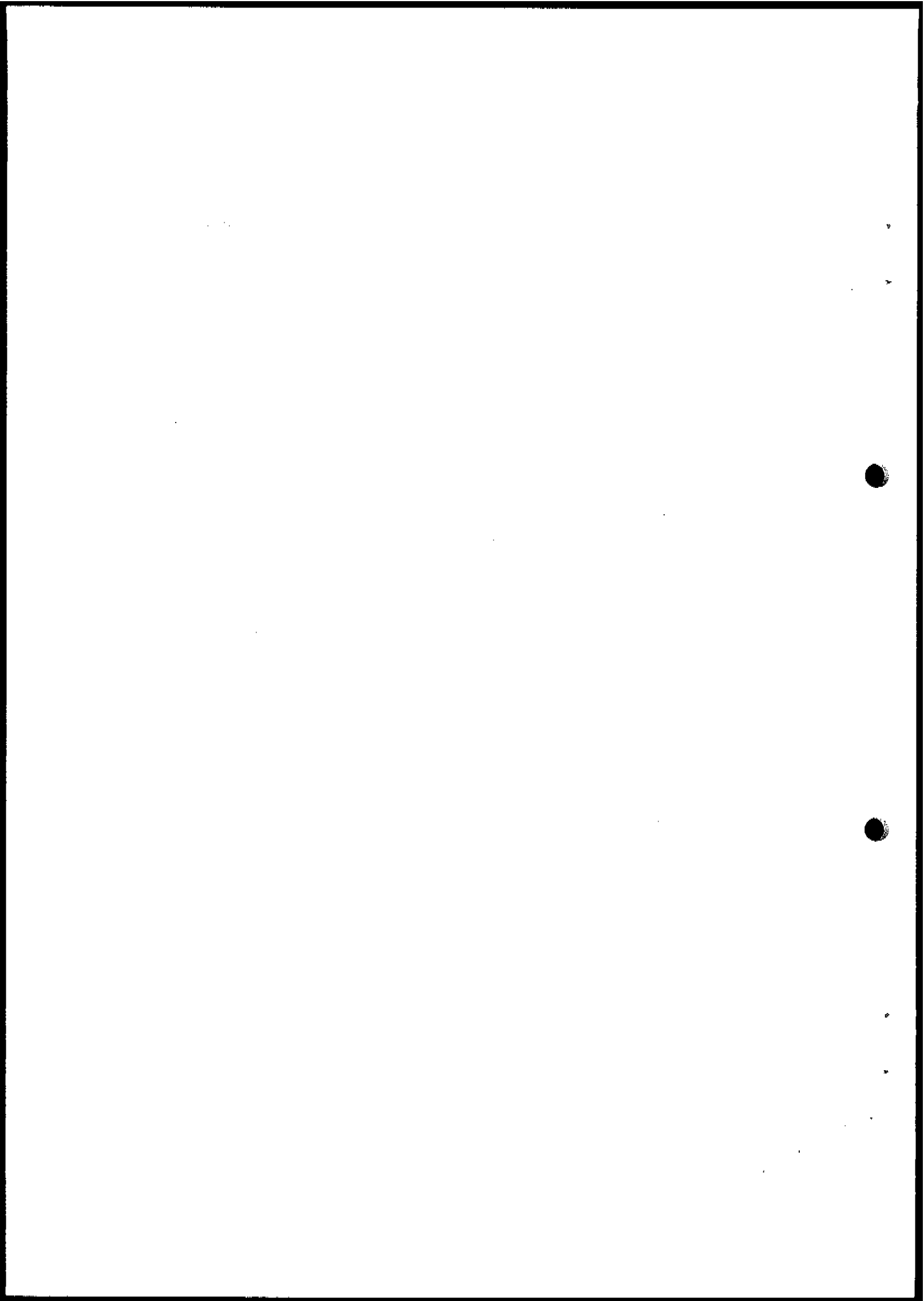
- Organization, facilitation, and follow-up to annual meetings of Heads of WHO Collaborating Centres for the Classification of Diseases.
- Administration of the mechanism for the periodic updating of the ICD and other members of the family of disease and health-related classifications. Receipt of proposed updates through the Collaborating Centres. Formulation of HST recommendations on each proposal for discussion and decision at the annual meetings of Heads of Centres.
- On the basis of the outcome of the Centre Head meeting, updating of the mainframe alphabetical index databases in English and French. Updating of the diskette and CD-ROM versions of the ICD in English and French and promulgation of the details of the agreed changes on the ICD Internet homepage. Notification to responsible groups of changes as they affect national language versions and specialty-based adaptations (e.g., ICD-O).
- Other maintenance of the ICD Internet homepage: listing of national language versions, implementation dates, updating of FAQs (frequently asked questions), etc.
- Support to the WHO mortality database.
- Support to users of the classifications.
- Further development and support to specialty-based adaptations
- Consultation with PLL on issues related to translation rights, copyright, and royalties.
- Administration of the Nomenclature Regulations with the Legal Counsel.
- Planning of activities and identification of budget requirements.
- Support to senior management for relevant activities of the WHO Executive Board and the World Health Assembly.



## WHO Long-term Strategy for the Development and Management of Health-Related Classifications

### Family of disease and health-related classifications





## WHO Long-term Strategy for the Development and Management of Health-Related Classifications

### PROCEDURES FOR UPDATING ICD-10

At their 1996 (Tokyo) meeting Heads of WHO Collaborating Centres for Classification of Disease confirmed the resolution of their 1995 (Canberra) meeting that all proposals for changes to ICD-10 must be sponsored by a Collaborating Centre and submitted to WHO through it. Proposals submitted directly to WHO will be returned to the originator with a request that they first be examined by the most appropriate Centre; addresses of Centres may be found in the Preface of the ICD-10 manual.

#### Changes to Index only

The Heads of WHO Collaborating Centres also agreed to modify the arrangements agreed at their 1995 meeting in respect of proposals for corrections to or additions to the index to ICD-10, as long as these were not associated with any changes to the Tabular List. Such proposals should:

- be advised to WHO by the sponsoring Centre no later than three months prior to the annual meeting of Centre Heads (for meetings in October, by the end of June), preferably in electronic form; copies to other Centres as early as practicable would also be appreciated
- be collated by the secretariat and advised to all Centres as soon as practicable and in any case be included in papers distributed prior to the annual meeting
- proposals accepted by the meeting of Centre Heads would become effective immediately and be publicized by both WHO and Centres through their distribution networks, including on world wide web sites
- all published lists of changes, in whatever form, would be cumulative, and each entry would be dated with the year of acceptance by Centre Heads and WHO

Proposals for changes to the Index which do not meet this timetable may be accepted by special resolution of a meeting of Centre Heads, or by correspondence, if considered sufficiently important.

**All other changes**

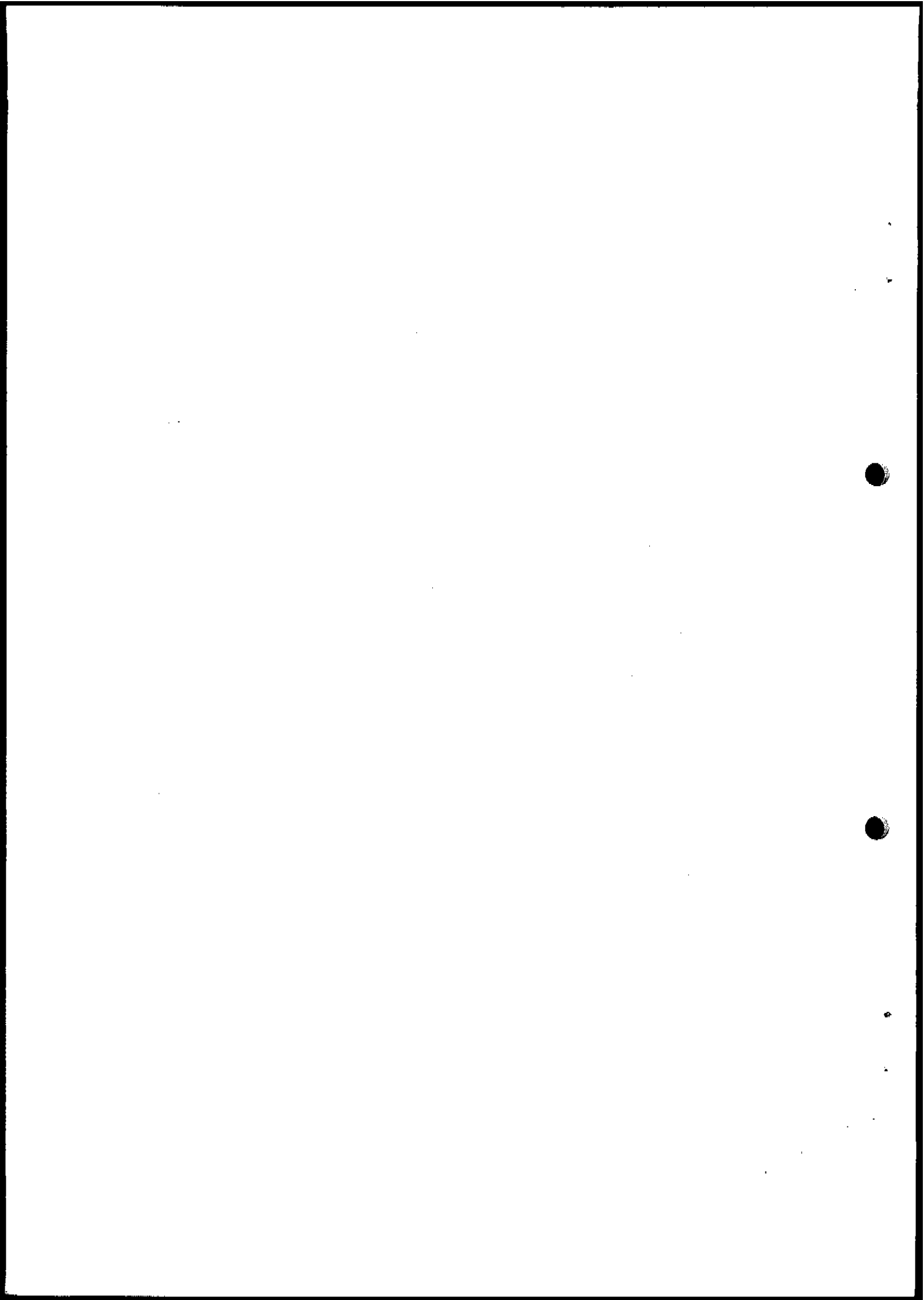
The Heads of WHO Collaborating Centres 1996 meeting confirmed that the procedures agreed at the 1995 meeting would continue to apply to all other proposals for changes to ICD-10, including Index changes consequent upon proposed changes in the Tabular List. Such proposals should:

- be advised to WHO by the sponsoring Centre no later than six months prior to the following meeting of Heads of Centres (e.g. for a meeting in October, by the end of April each year), preferably in electronic form; distribution of copies to other Centres would also be appreciated. Late submissions would NOT be accepted but held over for the following year
- be collated by WHO and distributed to Centres within one month of the closing date for receipt of submissions (by the end of May)
- be examined by Centres, which would respond to WHO within two months (by the end of July), preferably in electronic form. Copies of responses should if possible be sent other Centres
- be further collated by WHO and distributed with comments to Centres no later than one month before the Centre Heads meeting
- be considered by the annual meeting of Centre Heads
- if accepted be publicized by both WHO and Centres through their distribution networks, including on world wide web sites and put into effect by each Centre in accordance with its annual updating cycle but no later than the beginning of the calendar year commencing approximately 15 months after each Centre Heads meeting.

**WHO Long-term Strategy for the Development and Management  
of Health-Related Classifications**

**OTHER SPECIFIC ACTIVITIES PLANNED FOR THE PERIOD SEPTEMBER 1997  
- DECEMBER 1999**

- Development of three-character versions of ICD-10 in English and French for countries that do not have the infrastructure necessary to support the full four-character version.
- Revision of ICD-O-2 (ICD-O-3).
- Development of ICD-O-3 in French.
- Development of an International Classification of External Causes of Injuries.
- Finalization of Application of ICD-10 to Neurology (ICD-10-NA) and work on the French-language version.
- Revision of ICIDH in cooperation with the Division of Mental Health and Substance Abuse (MSA).
- NGO focal point for International Association of Cancer Registries (IACR) and World Organization of Family Doctors (WONCA).
- Facilitation of TENDON training courses in English and in French as requested by the Regional Offices.
- Preparation of guidelines for physicians and others certifying causes of death.
- Participation in the development of a taxonomic approach for the classification of medical procedures and the preparation of guidelines for the establishment of national procedure classifications.



**WHO Long-term Strategy for the Development and Management  
of Health-Related Classifications**

**REFERENCES TO THE GOVERNANCE AND FUNCTIONING OF CENTRE  
HEADS MEETINGS**

*Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases,  
London, UK, 27 March-2 April 1990*

“As a result of renewed concerns regarding the size of their annual meetings, the Centre Heads reconfirmed the rules on participation agreed at their 1982 meeting as follows:

1. The secretariat of the meeting is assumed by the SES unit. Other Headquarters and Regional Office staff may attend as part of the secretariat.
2. The Heads of Centres are by definition members of the meeting and may invite other persons as participants, with the prior approval of SES, to provide technical support.
3. The host Centre for each meeting is free to invite, with the prior approval of SES, in addition, persons from its own national offices or the geographical area of the Member States where the Centre is located.
4. The secretariat may invite representatives of Member States and nongovernmental organizations in official regions with WHO, as well as individual experts as participants or observers, subject to their technical competence in relation to the matters to be discussed and according to the WHO rules laid down for the attendance of such representatives or observers.
5. Invitations to other Heads of Centres will be sent by the host Centre. All other invitations will be sent by the secretariat.
6. Only the Heads of Centres or, in their absence, their nominated representatives have the right to vote. There is one vote only for each Centre.”

*Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases,  
São Paulo, Brazil, 9-15 April 1991*

“Rules on participation at annual meetings, originally agreed in 1982, were reconfirmed by the Centre Heads at the 1990 meeting in London. In view of the increased number of Centres and further increases anticipated over the next few years, it was considered appropriate to review or reaffirm the issues of periodicity of meetings and number of attendees as well as to agree on major agenda items or issues to be considered at future meetings.

The value of regular meetings as an opportunity to exchange information and ensure continuity was emphasized during the discussion and it was agreed that for the foreseeable future annual meetings should continue to be held. The timing of meetings in March or April and over a Tuesday to Monday period was still considered appropriate.

It was agreed that there may be occasions where issues related to the operation or administration of the Centres should be discussed at a smaller meeting restricted to the Centre Heads only. The most practical approach to this appeared to be a separate session at the time of the annual meeting. Otherwise, it was agreed that Centres, where possible, would limit their participation to three representatives per meeting.

With respect to topics or agenda items, these were expected to include: the review of the process of revision and implementation; review of proposals for update/change; review of Centre activity reports; review of issues related to the family of classifications; review of the report of activities of the SES unit; other matters of interest. It was anticipated that a major topic for the 1992 meeting would be ICD-10 reorientation training. At future meetings a specific topic might be selected in advance for discussion, e.g. morbidity applications."

*Meeting of Heads of WHO Collaborating Centres for the Classification of Diseases,  
Canberra, Australia, 10-16 October 1995*

"Delegates were reminded of the difficulty for the Chair, the Secretariat, and all delegates if papers were not distributed sufficiently early. It was suggested that papers ideally needed to be distributed at least six weeks before the meeting through the Secretariat in WHO Headquarters, or by direct mail or fax to all participants at least four weeks before the meeting. If these deadlines could not be met, Centre Heads should make every effort to fax papers before the meeting, in addition to bringing sufficient copies personally. It was agreed that these arrangements would greatly facilitate preparations for the meeting.

It was also agreed unanimously that all participants should receive an agenda showing which papers were to be discussed under each agenda item.

It was agreed WHO could arrange translation of papers from its official languages into English if submitted sufficiently early.

A suggestion that the report of the meeting be circulated more widely, for example to all countries, was supported. The Secretariat undertook to identify a suitable distribution list.

It was agreed the report should be accompanied by an 'Action list' to improve follow-up of decisions of the meeting.

The value of coordinated publication of reports of collaborative research had been mentioned earlier in the meeting. This would broaden the impact of work of the Centres; it was suggested for the multiple cause projects and for those relating to improvements in medical certification of cause of death. Coordinated publication would require an agreeable editor and at least one Centre being willing to lead a group of Centres.

Terms of reference of the Heads of Centres meetings were not widely known. They had last been agreed at the São Paulo meeting. A copy was distributed to delegates. It was noted that when votes were taken at the meeting, only Centre Heads or their designate had a vote; WHO Regional Office representatives did not.

Since each Centre represented either a language group or geographical area, Centre Heads were reminded of the need to communicate with their 'constituent' countries."