Lay reporting of health information



World Health Organization Geneva

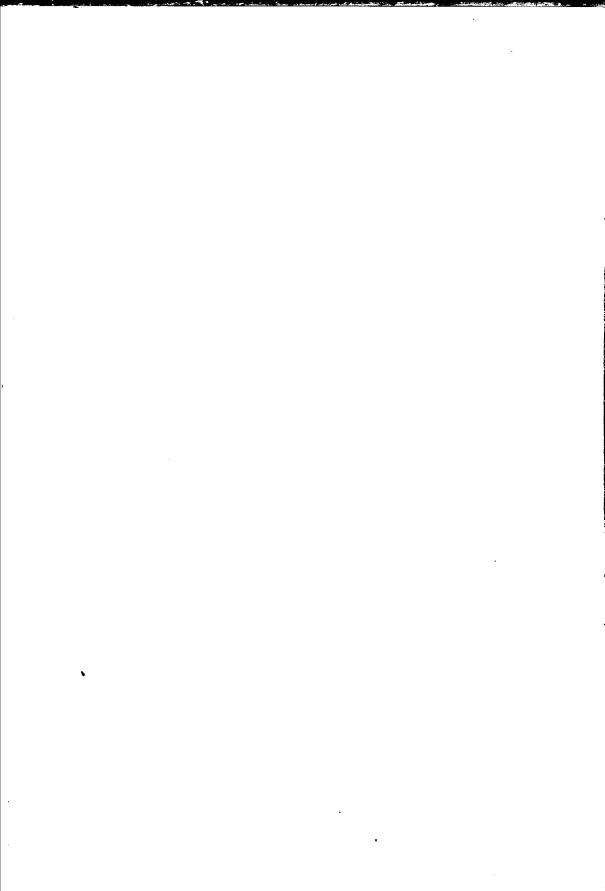
LAY REPORTING OF HEALTH INFORMATION

NOTIFICATIONS D'INFORMATIONS SANITAIRES
PAR UN PERSONNEL NON MEDICAL



WORLD HEALTH ORGANIZATION
GENEVA

1978



32 A

TABLE OF CONTENTS

| | | | | | | | | | | Page |
|---|---|---|---|---|---|---|---|---|---|------|
| What is "lay reporting"? | | | | | | | | | | 5 |
| Historical background | | | | | | | | | | |
| Role of present publication | | | | | | | | | | |
| Uses and users of data collected by lay reporting | | | | | | | | | | |
| Producers of the data | | | | | | | | | | |
| Content of the detailed list | | | | | | | | | | |
| Structure of the detailed list | | | | | | | | | | |
| | | | | | | | | | | |
| Recording and coding of the information | | | | | | | | | | |
| Reporting forms | | | | | | | | | | |
| Age grouping | | | | | | ٠ | ٠ | • | ٠ | 9 |
| Introducing a lay reporting system | | | | | | | | | | 9 |
| Queries and comments | • | • | • | • | ٠ | • | • | • | • | 10 |
| Detailed list of symptom associations for | | | | | | | | | | |
| lay reporting | | | | | | | | | | 11 |
| Alphabetical index to detailed list | | | | | | | | | | |
| Minimal mortality list | | | | | | _ | | | | 21 |
| Minimal morbidity list | | | | | | | | | | |
| | | | | | | | | | | |
| Death Record | | | | | | | | | | |
| Instructions for completion of Death Record | | | | | | | | | | |
| Patients' Register | ٠ | | • | | | | | | | 26 |
| Instructions for completion of Patients' Register | r | _ | | | | _ | _ | | | 27 |



LAY REPORTING OF HEALTH INFORMATION

WHAT IS "LAY REPORTING"?

In many areas of the world, a large proportion of the population has no access to health care provided by medically qualified personnel. This is particularly true, of course, of the developing countries. In these areas, health care is often provided by lay or paramedical personnel and is based on traditional methods or elementary medical training. The health information needed to indicate the existence of a health problem or to facilitate the management of primary health care systems needs must be provided by these same personnel. The term "lay reporting" has come to be used to describe methods of achieving the provision of this information.

HISTORICAL BACKGROUND

The first expression of WHO interest in lay reporting of health data was a paper by Dr Yves Biraud in 1956 (unpublished document WHO/HS/60, 1956). A WHO group, meeting in Geneva in 1971, discussed the problem of utilizing the International Classification of Diseases (ICD) in lay reporting of morbidity and deaths in developing countries. This group recommended a classification and practical methods of recording signs, symptoms and complaints and recommended practical studies (unpublished document WHO/ICD/71.6, 1971). In 1973 WHO convened another consultation in Geneva to assess the value of lay reporting, particularly to provide much-needed information on maternal and perinatal deaths (unpublished document WHO/ICD/LR/73.6, 1973).

The International Conference on the Ninth Revision of the International Classification of Diseases (ICD) in 1975 also discussed lay reporting. The suitability of the ICD for reporting information furnished by persons other than physicians was subject to wide divergence of opinion. A small working party of the Conference developed a recommendation that WHO become increasingly involved in attempts by Member countries to develop methods of using lay and paramedical personnel in the collection of morbidity and mortality statistics. This should be done by organizing meetings to facilitate the development of systems of classification and methods of recording and by assisting countries in their endeavour to

establish and expand such methods (unpublished document WHO/ICD9/Rev.Conf./75.24 Rev.1, 1975).

In accordance with this recommendation, a Working Group, convened by the WHO Regional Office for South-East Asia (SEARO), met in Delhi, 22-27 November 1976, and drew up a detailed list of symptom associations, susceptible of recognition by primary health services personnel (who are not medically qualified by commonly-accepted standards) and indicative of conditions that were important health problems in various parts of the world. From this detailed list were derived two shorter lists, one for causes of death (Minimal Mortality List, page 21) and the other for reasons for contact with health services (Minimum Morbidity List, page 22).

Field trials of this system were carried out in countries of the Region, as a result of which a revision of the list of symptom associations and of the reporting forms was made. It is this revision that is now presented.

ROLE OF PRESENT PUBLICATION

It must be emphasized that a system developed for one area or region cannot simply be transplanted to another and used there without modification. Other areas will have different health problems to be identified, different standards of personnel, and different descriptions of presenting symptoms, whether in English or another language. This publication should be regarded as merely an example of a lay reporting system, requiring adaptation to other circumstances.

USES AND USERS OF DATA COLLECTED BY LAY REPORTING

The purpose of collecting health information is twofold: (a) for epidemiology and prevention, to alert the health authorities to the emergence of a health problem (for example, an increase in cases of an infectious disease indicating the possible start of an epidemic), and (b) to facilitate the management of primary health care (planning, operation, evaluation).

Both of these are of concern not only to the central or regional authorities), but also at the local level. The data, therefore, should be analysed at the periphery as well as being reported up to the next administrative echelon.

PRODUCERS OF THE DATA

The SEARO Working Group mentioned above discussed the diverse categories of lay or paramedical personnel providing services at the more remote areas and basic levels of health care, and concluded that the qualifications for a person involved in the kind of recording and reporting in question were:

- (a) the ability to read and write easily,
- (b) sufficient maturity to accomplish the assigned tasks,
- (c) acceptance, and preferably selection, by the community served, and,
- (d) sufficient practical experience in health services to recognize the complaints given in the categories used for recording and reporting.

CONTENT OF THE DETAILED LIST

No attempt has been made to identify all the causes of morbidity likely to be met; instead identification has been limited to conditions that are important because of their frequency, their gravity or their cost to the community. Thus, constipation, though occurring very commonly, was not considered important enough to warrant separate identification.

They must also, of course, be able to be recognized by the reporting personnel. Certain conditions are susceptible of such recognition only when the reporting personnel have been specially trained or when they are endemic in the area or when a proven epidemic of the disease is in progress. Such conditions are marked with an asterisk (*) in the detailed list.

STRUCTURE OF THE DETAILED LIST

The list consists of nineteen groups of morbid conditions, plus a twentleth group for unknown causes, a list of external causes of violence and a list of services. Each of the nineteen groups is based on the occurrence of "a main or lead symptom or symptoms", common to all the conditions in the group: differentiation within the groups depends on the occurrence of additional symptoms or descriptors. A symptom that is the "main symptom" for one group (i.e. the most significant symptom for

all conditions in that group) may, of course, appear as an "additional symptom" for a condition in another group, where it plays a subordinate role in the diagnostic pattern. Thus, fever is a main symptom in groups 01, 02 and 03 and an additional symptom in group 08, where cough is the main symptom. In the alphabetical index, main symptoms are indexed as main terms, starting at the left-hand margin, with the additional symptoms or descriptors indented beneath them. Thus the combination of cough and fever is indexed under the main term "cough" and not under "fever".

The E group for external causes of injuries should be used as an additional code when the main code is from groups 18 or 19 (injuries). The S group for health services should be used when patients without current complaint or sickness attend solely for the purposes listed. The terms and conditions in these two groups do not appear in the alphabetical index.

Neither the arrangement of morbid conditions nor their code numbers bear any relationship to the International Classification of Diseases (Ninth Revision). To have attempted an integration with this ICD-9 coding system would have made the list much more complex. Frequencies for the conditions identified in the list can, of course, always be compared with those for the corresponding ICD-9 categories derived from other sources.

RECORDING AND CODING OF THE INFORMATION

The reason for contact with the health service should be recorded as volunteered by the patient himself or as elicited by questioning. It should not be distorted to fit into one of the rubrics on the list.

The statement thus recorded should then be coded, according to whatever coding system is selected (see pages 9-10), as a separate operation, either by the same person who did the recording or by someone else. If the patient's statement indicates that one or more different morbid conditions were present, then the one to be coded should be the most severe, or, if information about severity cannot be ascertained, the one first mentioned by the patient.

REPORTING FORMS

Suggested forms for a Death Record and for a Patients' Register and instructions for their completion were drafted by the SEARO Working Group. They appear on pages 24-27 as models that may be amended and adapted as required to fit different circumstances.

AGE GROUPING

Age should be recorded for all patients and deaths in sufficient detail to allow the data to be tabulated according to the following age groups:

under 7 days
7 - 27 days
28 days - under 1 year
1 - 4 years
5 - 14 years
15 - 44 years
45 - 64 years
65 years and over

INTRODUCING A LAY REPORTING SYSTEM

As noted earlier, the contents of this document should be regarded as an example, needing to be modified and adapted to fit different national circumstances. The steps that need to be taken when making such a modification can be summarized as follows:

- Identify the health problems concerning which data are required, taking into account their prevalence, severity, cost to the community, and whether they are the object of special programmes or are required to be notified or referred to another echelon.
- 2. See whether the minimal lists for mortality and morbidity include all the health problems identified under 1 above. If not, add items from the detailed list for the missing conditions. If necessary, add to the detailed list, describing conditions in terms of symptom associations recognizable by the lay personnel who will be operating the scheme.

- 3. Express the modified mortality and morbidity lists in terms of the language used locally by the lay personnel and construct an alphabetical index on the lines of the one on pages 16-20.
- 4. Look at the reporting documents and the instructions for their completion on pages 24-27 and modify them as necessary to suit the circumstances in which they will be used.
- 5. Train the personnel who will operate the scheme. The SEARO Working Group considered that one day's training was sufficent, consisting of 2 hours of explanation and the rest of the day spent in practice.
- 6. Establish the chain of transmission of the data collected, ensuring that it is exploited at each successive level where some decision-making is required, whether for preventive measures or for management of the health services.

The World Health Organization will be happy to assist countries in introducing such a system.

QUERIES AND COMMENTS

This is the first attempt by the World Health Organization to establish an organized method for the collection of health information by lay or paramedical personnel and the approach is, therefore, to a great extent experimental. In order to improve and refine the system, it is essential that countries feed back their experience to WHO. Comments, suggestions and evaluation should be addressed to:

Chief Medical Officer
International Classification of Diseases
World Health Organization
Avenue Appia
1211 Geneva 27
Switzerland



DETAILED LIST OF SYMPTOM ASSOCIATIONS FOR LAY REPORTING

Conditions marked with an asterisk (*) should be used only by health workers having sufficient experience to recognize them, or when the conditions are endemic in the area, or during proven epidemics.

| Mai | n sympt Addit | om(s) ional symptom(s) or description(s) | Possible diagnosis |
|-----|------------------|---|----------------------------------|
| 01 | Fever | with skin manifestations | |
| | 010 | Fever with red rash, disappearing in several days | Measles |
| | 011 | Fever with vesicular blisters, healing clear | Chickenpox |
| | 012 013 | Fever with pustules, healing with pitting Fever with yellow skin, yellow whites of eyes, discoloured stools, articular pains | Smallpox* Infectious jaundice |
| | 014 019 | High fever with skin symptoms of 013 Fever with other and unspecified skin manifestations | Yellow fever* |
| 02 | Fever | with neurological problems | |
| | 020 | Fever with prostration, ocular paralysis, muscular pains | Encephalitis* |
| | 021 | Fever with prostration, severe headache, articular pains | Dengue* |
| | 022 | High fever with prostration, painful glands, bubo | Plague* |
| | 023 024 | Fever with paralysis Fever with neck rigidity, vomiting, | Poliomyelitis Meningitis* |
| | 029 | skin rash Fever with other and unspecified neuro- | Ü |
| | 023 | logical manifestations | |
| 03 | Other | fevers | |
| | 030 | High fever, intermittent, with chills, prostration | Malaria* |
| | 031 038 | As 030, with laboratory confirmation Fever with other associated symptoms | Malaria, confirmed |
| | 039 | Fever, unqualified | |
| 04 | Skin | lesions (see also 01) | |
| | ⋄ 040 | Anaesthetic skin lesions (leprous), deformities, loss of extremities | Leprosy* |
| | 041 | Crusted ulcerations | Yaws* |
| | 042 | Fibrous nodules, blindness | Onchocerciasis* |
| | 043 | Cord-like nodules, swelling of extremities | Filariasis* |
| | 044 | Dry skin and mucosa, depressed fontanelles in children | Dehydration* |

| | 045 046 047 | Pale skin and mucosa, weakness, fatigue Yellow skin, yellow whites of eyes Skin abscess or infection, after injection or operation | Anaemia* Jaundice |
|----|-------------------|---|--|
| | 048 | Painless ulcer, raised edges, genital area, history of sexual contact | Syphilis* |
| | 049 | Skin sores and ulcerations, other and unspecified | |
| 05 | Diarr | hoea and vomiting | |
| | 050 | Diarrhoea and vomiting, massive dehydration, watery stools | Cholera* |
| | 051 | Diarrhoea and vomiting, abdominal pain | Food poisoning* |
| | 052 | Diarrhoea and vomiting, fever, sputum- like stools | Bacillary dysentery* |
| | 059 | Diarrhoea and vomiting, other and unspecified | |
| 06 | Other | diarrhoeas | |
| | 060 | Diarrhoea, abdominal pain, mucopurulent and bloody stools | Amoebic dysentery* |
| | 061 | Diarrhoea, abdominal pain, fever | Infectious diarrhoea |
| | 069 | Diarrhoea, unqualified | Diarrhoea |
| 07 | | abdominal problems | |
| | 070 | Abdominal pain, rigidity of abdominal wall | |
| | 071 072 | Abdominal pain, vomiting | Indigestion |
| | 072 | Abdominal swelling Rectal pain, blood in stools | Tumour, ascites Haemorrhoids |
| | 074 | Worms in stools or vomitus | Intestinal parasites |
| 08 | Cough | | paradical paradical |
| | _ | | |
| | 080 | Chronic cough (3 months or more), loss of weight, blood in sputum, slight fever | Tuberculosis* |
| | 081 | As 080, with laboratory confirmation | Tuberculosis, confirmed |
| | 082 | Acute cough, fever, chest pain, shortness of breath | Pneumonia |
| | 083 | Acute cough, fever, muscular pain, headache, nose and throat discomfort | Influenza |
| | 084 | Acute cough, fever, typical whoop | Whooping cough |
| | 085 | Acute cough, fever | Acute bronchitis |
| | 089 | Cough, other and unspecified | |
| 09 | Upper | respiratory infections | |
| ` | 090 | Nose and throat discomfort, watery discharge, cough, fever | Common cold, upper respiratory infection |
| | 091 | Sore throat, fever, difficulty in swallowing | Sore throat |
| | 092 | Sore throat, false membrane, slight fever | Diphtheria* |

| 10 | Breatl | hing problems | |
|----|------------|--|--|
| | 100 | Breathing difficulty, shortness of | Heart disease* |
| | 100 | breath, chest pain, swollen ankles | neare arsease |
| | 101 | Breathing difficulty, shortness of breath, cough | Asthma, emphysema, chronic bronchitis* |
| 11 | Uroge | nital manifestations | |
| | 110 | Sugar in urine, thirst, hunger, | Diabetes |
| | 111 | frequent urination Blood in urine | Schistosomiasis* |
| | 112 | Burning pain during urination, fever, pus in urine | Renal infection |
| | 113 | Burning pain during urination, discharge of pus from urethra (male) | Gonorrhoea |
| | 114 | Cessation of urination | Renal shutdown |
| | 115 | Cessation of urination, pain, distension | Urinary obstruction |
| | 116 | Vaginal discharge, fever, low abdominal pain | Genital infection |
| | 117 | Menstruation disorders | Menstruation disorders |
| 12 | Eye m | anifestations | |
| | 120 | Nontransparent patches on eye | Eye opacities* |
| | 121 | Sore eyes, discharge, painful swollen lids | Eye infections |
| | 122 | Blindness | 7/14 A 1-0/ |
| | 123 124 | Night blindness Low vision | Vitamin A deficiency |
| | 125 | Other eye complaints | |
| | 123 | other eye compraines | |
| 13 | Other | head and neck manifestations | |
| | 130 | Ulceration, pain, tongue or mouth | |
| | 131 | Toothache | |
| | 132 | Bleeding from nose or mouth | |
| | 133 134 | Other mouth problems | California |
| | 134 | Swelling of neck, painless, moves on swallowing | Goitre |
| | 135 | Ear pain, discharge | Ear infections |
| | 136 | Hearing difficulties | |
| 14 | Neuro | logical manifestations | |
| | 140 | Fear of drinking water, convulsions, history of animal bite | Rabies* |
| | 141 | Locked jaw, muscular spasms, history of open wound or childbirth | Tetanus* |
| | 142 | Paralysis, sudden, with unconsciousness | Stroke* |
| | 143 | Severe headache, dizziness | Hypertension* |
| | 144 | Abnormal behaviour, confusion | Mental disorders |
| | 145 | Excessive use of alcohol, with physical, | Alcohol abuse |
| | 146 | mental and social deterioration | D 1 |
| | 140 | Use of drugs for nonmedical purposes, with physical, mental and social | Drug abuse |
| | | deterioration | |

| | 147 | Convulsions, with unconsciousness | Epilepsy* |
|----|------------|--|-----------------------------|
| | 148 149 | Paralysis, unspecified | |
| | 149 | Unconsciousness, coma, unspecified | |
| 15 | Mater | nal problems | |
| | 150 | Pregnancy, normal | |
| | 151 | Pregnancy with problems such as bleeding from genital tract, swelling of legs, urinary infections, fever, anaemia | Complicated pregnancy |
| | 152 | Abortion | Abortion |
| | 153 | Childbirth, normal | |
| | 154 | Childbirth with problems such as excessive bleeding, difficult birth, exhaustion from long labour, premature rupture of membranes (dry birth) laceration of genitals or perineum | Complicated child- birth |
| | 155 | Puerperium with problems such as infection | Complicated |
| | | or laceration of genitals, fever, prolapse | puerperium |
| 16 | Newbo | rn problems | |
| | 160 | Normal livebirth | |
| | 161 | Born dead | Stillbirth |
| | 162 | Injured during birth by passage or manipulation | Birth injury |
| | 163 | Small or premature baby | Immaturity |
| | 164 | Body or limbs misshapen, or functions not working properly | Congenital anomaly |
| 17 | Gener | al problems | |
| | 170 | Weakness, loss of weight, anaemia, oedema, history of inadequate diet | Malnutrition* |
| | 171 | As 170, with reddish discolouration of hair or skin in coloured races | Kwashiorkor* |
| | 172 | Weakness, pallor, fast and weak pulse, prostration | Shock |
| | 173 | Weakness, tiredness, unspecified | |
| | 174 | Weight loss, unspecified | |
| | 175 | Pain and swelling in joints or muscles | Arthritis, rheumatism |
| | 176 | Pain, not elsewhere classified | , |
| | 177 | Swelling, not elsewhere classified | |
| | 178 | Impaired physical or psychological | Senility |
| | | function due to old age (not to be used for patients under 65) | |
| 18 | Serio | us injuries (require more than dressing) | |
| | | _ | |
| • | 180 | Fractures | |
| | 181 | Dislocations | |
| | 182 | Traumatic amputations | |
| | 183 | Avulsion | |
| | 184 185 | Haematomas | |
| | 186 | Crushing injuries | |
| | 187 | Foreign bodies in orifice | |
| | 188 | Burns Poisoning (other than food maintain) | |
| | 189 | Poisoning (other than food poisoning) Other serious injuries | |

- Mild injuries (require cleaning and dressing only) 19
 - 190 Lacerations
 - 191 **Punctures**
 - 192 Bruises
 - 193 Sprains
 - 194 Strains
 - 195 Contusions
 - 196 Abrasions
 - 199 Other mild injuries
- 20 Other and unknown causes of morbidity and mortality
 - 200 Other specified causes
 - 201 Sudden death from unknown cause
 - 202 Unknown cause
- E 1 External causes of injuries
 - E 10 Bites or stings of venomous animals
 - E 11 Accidental burns
 - Accidental drowning Accidental falls E 12
 - E 13
 - E 14
 - Accidental poisoning (other than food poisoning)
 Transport (traffic) accidents (involving railway,
 boats, aircraft, motor vehicles, other vehicles, E 15 animals being ridden or drawing vehicle)
 - Other accidents E 16
 - Suicide, self-inflicted injury E 17
 - E 18 Homicide, assault
 - E 19 Violence, unknown whether accident, self-inflicted or assault
- S 1 Health services provided
 - S 10 External applications
 - S 11 Injection, vaccination
 - S 12 Oral medication
 - S 13 Dressing of wounds
 - S 14 Normal delivery
 - S 15 Other procedures
 - S 16 Maternal and child health consultation
 - S 17 Family planning consultation
 - S 18 Other consultation
 - S 19 Other service

ALPHABETICAL INDEX TO DETAILED LIST

```
Abdomina1
- pain (with)
- - rigidity of abdominal wall 070
- - vomiting 071
- swelling 072
- tumour 072
Abnormal behaviour, confusion 144
Abortion 152
Abrasion 196
Abuse
- alcohol 145
- drug 146
Acute abdomen* 070
Amoebic dysentery* 060
Amputation, traumatic 180
Anaemia* 045
Arthritis 175
Ascites 072
Asthma 101
Avulsion 183
Bacillary dysentery* 052
Birth injury 162
Bleeding from nose or mouth 132
Blindness 122

    night 123

Blood in urine 111
Breathing difficulty, shortness of breath (with)
- chest pain, swollen ankles 100
- cough 101
Bronchitis (chronic) 101

    acute 085

Bruise 192
Burn 187
Cessation of urination (with) 114
- pain, distension 115
Chickenpox 011
Childbirth (normal) (with) 153
- complicated 154
- difficult 154
- dry 154
- excessive bleeding 154
- exhaustion from long labour 154
- laceration of genitals or perineum 154
- premature rupture of membranes 154
Cholera* 050
Coma 149
Common cold 090
Congenital anomaly 164
Constipation 200
Contusion 195
Convulsions, unconsciousness 147
Cough 089
- acute, with fever (with) 085
- - chest pain, shortness of breath 082
```