Local environmental health concerns

risk communication, exposure assessment and cluster investigation

Gezondheidsraad **Vice-President**
Health Council of the Netherlands

To the Minister of Housing, Spatial Planning and the Environment

Subject	: Advisory report on "Concern about local environmental factors"
Your reference	:
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Dear Minister,

Hereby I offer you an advisory report about the occurrence of health problems that, according to the opinion of the local population, may be caused by the physical environment. It has been drawn up by a Health Council of the Netherlands' Committee that was established by me for this purpose and reviewed by the Standing Committee on Health and Environment. I also offered this advisory report today to the Minister of Health, Welfare and Sport.

The advisory report presents a description of the scientific literature about the subject as well as a sketch of the approach to local environmental problems in practice.

The Committee has limited itself to recommendations about how to deal with expressions of concern about the influence of local environmental factors on health. Governmental responses to large-scale (environmental) accidents or disasters are outside the scope of the present report.

The recommendations contained in the advisory report are intended as guidelines for practice. Their validation, evaluation and (if necessary) adjustment by Municipal Health Authorities and other local agencies. This will require the participation of all stakeholders.

Sincerely Yours,

(signed),
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to:

the Minister of Housing, Spatial Planning and the Environment

the Minister of Health, Welfare and Sport

Nr 2001/10E, The Hague, 3 April 2001

The Health Council of the Netherlands, estabhlished in 1902, is an independent scientific advisory body. Its remit is “to advise the government and Parliament on the current level of knowledge with respect to public health issues...” (Section 21, Health Act).;

The Health Council receives most requests for advice from the Ministers of Health, Welfare & Sport, Housing, Spatial Planning & the Environment, Social Affairs & Employment, and Agriculture, Nature Preservation & Fisheries. The Council can publish advisory reports on its own initiative. It usually does this in order to ask attention for developments or trends that are thought to be relevant to government policy.

Most Health Council reports are prepared by multidisciplinary committees of Dutch or, sometimes, foreign experts, appointed in a personal capacity. The reports are available to the public.

This report can be downloaded from www.gr.nl

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Contents

Executive summary

Concerned citizens are increasingly contacting local authorities to ask whether seemingly unusually large numbers of similar health complaints or disorders in their neighbourhood (a 'disease cluster') may be related to exposure to local environmental factors. The President of the Health Council of the Netherlands consequently instructed an *ad hoc* Health Council Committee to produce an advisory report on epidemiological research methods in response to public concerns about local environmental health issues and aspects of risk perception and risk communication.

The Committee detailed its task as follows:

1 Compile and evaluate the possibilities and limitations of risk communication in situations of local environmental health concerns, with attention to the differences in risk perceptions of the parties involved.
2 Compile and evaluate the possibilities and limitations of a risk assessment in situations of suspected exposure to local environmental factors.
3 Compile and evaluate the possibilities and limitations of research into possible relations between local environmental factors and disease clusters, as observed by the public.

According to an estimate of the National Institute of Public Health and the Environment (RIVM), two to five percent of the total number of disability adjusted life years in the Dutch population is attributable to environmental pollution. Besides air and noise pollution caused by traffic, factors in the indoor environment make the largest contribution, especially in the form of dampness, radon and passive smoking. The relatively large

impact of general risk factors, including demographic and socio-economic characteristics, as well as life style, makes it difficult to determine the direct effect of physical or chemical environmental factors on local differences in the occurrence of diseases or health complaints. The health status of a neighbourhood or district may for instance depend significantly on the local age distribution.

In view of the natural variation in place and time, a concentration of certain disorders in a particular area may also be based on coincidence. However, it is understandable that people note such a disease cluster and report it, especially if they are concerned about the quality of the local environment.

Concern about health effects of exposure to local environmental factors may lead people to experience, notice and report health problems, particularly non-specific health complaints, such as headaches, dizziness and tiredness. This is apparent from various studies on the prevalence of such health complaints attributed to environmental pollution, such as waste dumps, air pollution and electromagnetic fields. Sensory observations, such as odour and noise nuisance may play a role in this. It is striking that many complaint patterns display similarities, regardless of the differences in exposure to hazardous agents. If a somatic cause cannot be found, the complaints are categorised as 'medically unexplained'. Such physical complaints do not arise directly from the exposure but indirectly through uncertainty and concern. They occur often if residents experience a lack of control of the situation or if they have no trust in the authorities concerned. This process of chronic stress, symptom perception and attribution may be reinforced by authorities or health care workers playing down health problems or by the media magnifying them. The Committee believes that insight into and the recognition and acceptance of the effect of stress factors on health could prevent a (further) increase in medically unexplained complaints in stressful situations.

Risk perception and risk communication

When assessing the risks, experts place the emphasis on quantitative data, whereas citizens are much more likely to base their opinions on qualitative aspects, such as the nature and origin of the contamination to which they consider to be exposed, usually involuntarily. For example, when evaluating risks, members of the public take into account considerations such as the lack of familiarity with or lack of control over the pollution or its source. They also take into consideration the uncertainty about the possible health risks, the credibility of the source of the information and the level of trust in the executive or supervisory bodies. The discrepancies between the public's opinion about the risk and that of the risk assessors or the authorities can create a great deal of tension. The government cannot therefore do with scientific explanations of the risks but must also pay particular attention to the risk perception of all parties involved.

In the case of local environmental health problems, the Committee believes early risk communication is extremely important, in the sense of an exchange of information and opinions between the authorities, the public and the other parties involved about the nature and extent of the risk.

Proper risk communication can help ensure that those involved are able to form a considered opinion about any risks posed by local environmental factors and can help create greater understanding and trust between the parties. In this respect, the Committee believes the involvement of local residents is a precondition for an effective policy to address a local environmental health problem. If notified in good time about research results, for example, the media can play a positive role in this area too.

The Committee believes that guidelines for risk communication and citizen participation may be useful in the approach to local environmental health problems, although hardly any research has been conducted into the efficacy of such guidelines. Risk communication and public participation are not only important in making a hazardous situation controllable. There must also be sufficient opportunity for an anticipatory policy on environmental health. This could lay the foundations for a better relationship based on trust between the authorities and the public, which could possibly prevent unjustified concerns arising.

Exposure assessment

The most suitable instrument for evaluating possible health effects of exposure to environmental factors is a risk assessment. An important feature of risk assessment is the comparison between the degree of exposure and health-based recommended exposure limits.

In the case of local environmental health problems, estimating external exposure by determining the concentrations in water, air, soil or crops will generally suffice. The Committee believes that a determination of internal exposure (body burden) will only be necessary in exceptional cases and only if certain conditions are met. The possible advantages of this, such as reducing the uncertainty or concern about any effects on health have to be weighed against the disadvantages, such as difficulties with interpreting individual measurement results.

On the basis of an exposure and risk assessment it can be determined whether the exposure exceeds relevant health-based limits and whether measures or advice on behaviour are necessary to reduce the health risks. The transparency of the entire process is important, as an exposure and risk assessment can be fairly complex. As far as possible, the perspective and knowledge of those concerned must be taken into account.

Cluster investigation

Questions from the public about disease clusters that are attributed to environmental exposures by those reporting them are often addressed to the Municipal Health Service, which is assigned a task in this area by the Public Health Act. The Committee is in favour of the stepwise approach the Municipal Health Services take to disease clusters. This approach is now widely supported and distinguishes between 3 phases (orientation, verification and quantification) and 3 tracks (the health, environmental and relationship track). In a survey among Municipal Health Services of how they dealt with suspected disease clusters in the years 1993 to 1997, it emerged that already in the verification phase the number of health problems in the potentially exposed population was found not to differ from what would be expected on the basis of global population characteristics.

If the verification phase of a cluster study does support the suspicion that a disease cluster exists, it is advisable to use the data from existing health registries to investigate the degree to which the number of disease cases has increased. The Committee's preferred practice for adoption by the Municipal Health Service is the calculation of standardised morbidity ratios for the area concerned, rather than the use of advanced cluster analysis methods, the most of which are too complex for decentralised use.

Little significance can be attached to the results of statistical testing, performed after the cluster has been noticed. The reason for this is that testing afterwards does not meet the fundamental condition for the validity of a statistical test, as no real random sample has been taken. Moreover, the delineation in terms of place and time is only made afterwards.

If more health problems are found than were expected, it is worthwhile considering a study of the occurrence of the disorder in earlier periods or in other areas with a comparable level of exposure. The delineation in terms of place and time can then be chosen in advance, on the basis of the exposure, in order to avoid bias of the results. The Committee believes that any such supra-regional study, which may also use advanced techniques, should be conducted by or in co-operation with organisations with expertise in spatial statistics and cluster analysis.

Further epidemiological research

If a disease cluster has been shown to exist ánd if a proper exposure assessment makes it plausible that the local environmental exposure is or has been sufficiently high to cause health effects, further etiological epidemiological research may be considered. Research of this kind, in which health data and exposure data are collected at the individual level,

is intended to determine a possible link between personal exposure to environmental pollution and particular health effects. As a rule, this is only worthwhile if the study will be conducted under strict conditions; especially the number of cases has to be sufficiently high. If the conditions are not met, the disadvantages may outweigh the benefits, especially if the research is combined with blood and urine analysis. It is therefore essential to discuss beforehand with those concerned about the possibilities and limitations of the investigation, in order to avoid creating expectations that cannot be met.

Recommendations

The Committee has defined the following aspects as important elements in any pragmatic approach of local environmental health problems by public bodies:

- take worries about exposure to local environmental factors seriously
- pay attention at an early stage to risk communication and public participation
- perform a systematic and transparent exposure assessment
- consider exposure reducing measures in the case of any nuisance or undesirable exposure
- pay attention to any possible somatic consequences of stress
- follow a stepwise approach to environment-related disease clusters
- take into account coincidence as an explanation of detected disease clusters
- be critical when conducting descriptive epidemiological studies
- explain under which conditions a further epidemiological study would be advisable
- involve communication specialists in epidemiological studies.

The Committee recommends that the government supports citizen groups and environmental organisations in the publication of a 'citizen's guide' to risk, risk communication and participation. Some guidelines were recently drafted in the Netherlands for resident participation in soil remediation operations and health issues relating to specific local environmental problems. The Committee also believes that Municipal Health Services draw up guidelines on dealing with concerns about the possible health effects of local environmental factors. A start has now been made on this. Another condition for a proper approach to local environmental health problems is adequate expertise and time for risk communication. The Committee believes more attention should be paid to communication and participation in environmental health, before questions and complaints arise.

With regard to the undeniable existence of knowledge gaps, the Committee believes that more detailed information is required about the effectiveness of guidelines in risk communication. The Committee also calls for more research into the degree to which and the way in which psychosocial factors affect the experience and reporting of health

complaints, especially with regard to hazards that are believed to exist in the local environment.

Chapter 1

Introduction

Concerns about local environmental pollution are increasingly being expressed in the form of reports of unusually high numbers of similar health complaints or disorders in a particular area (RIVM99b). Many of those concerned attribute such a ‘cluster of diseases’ to chemical, physical or biological environmental factors: soil pollution, waste dumps, waste incinerators, power lines, TV and radio transmitters, drinking water, an so forth. An example of this occurred in the nineteen nineties, in the Dutch village of Weurt: within a very short period, several young women in a single street died of cancer (GGD95). Surrounding residents believed it was no coincidence and looked for the cause in emissions from a nearby industrial estate. Research by the municipal health service in the area initially confirmed a higher incidence of cancer but investigators thought it unlikely that local environmental factors had played a role. However, this assessment failed to ease concerns in the neighbourhood. Similar situations also occurred around an electrical high-tension line in Odijk and at a waste dump in Sliedrecht (Had98, GGD00).

1.1 Committee's task

The question arose in the Health Council's Standing Committee on Health and the Environment about the extent to which epidemiological studies could be useful in assessing concerns about local environmental factors and especially about disease cluster problems that are said to be linked to them. More generally, the standing committee believed an insight was needed into the possibilities available to the government for effectively dealing with any such cases. After this subject was placed on the Health Council’s pro-

gramme of activities (see annex A), a Committee was set up (see annex B) that was not only given the task of studying the pros and cons of existing investigative methods but also that of examining the differences in risk perceptions of those involved and in the risk communication between them.

The Committee detailed its task as follows:

- Compile and evaluate the possibilities and limitations of risk communication in situations of local environmental health concerns, with attention to the differences in risk perceptions of the parties involved.
- Compile and evaluate the possibilities and limitations of a risk assessment in situations of suspected exposure to local environmental factors.
- Compile and evaluate the possibilities and limitations of research into possible relations between local environmental factors and disease clusters, as observed by the public.

For the purposes of this advisory report, the Committee defines a local environmental problem as a situation in the local physical environment that various people consider to be detrimental. This often involves concerns about adverse health effects of environmental factors that apply in the local environment of the residents of a street, neighbourhood, district or village. Local government is primarily responsible for dealing with questions and complaints of this kind.

The Committee restricted itself to dealing with expressions of concern about health that are related to local environmental problems. Government action as a result of major (environmental) calamities and disasters is beyond the scope of this advisory report. Given its task, the Committee also does not discuss unrequested or anticipatory recommendations nor communications on the health aspects of the local environment, although these may well prevent some of the problems that will be discussed. There are overlaps between a reactive and more active approach to local environmental problems, particularly in the area of exposure assessment and risk communication.

A terminology list is enclosed as annex C.

1.2 Organisation of this advisory report

Chapter 2 contains background information on the relationship between local environmental problems and health. The Committee examines the mechanisms that form the basis for experiencing and explaining local variations in the occurrence of health complaints and disorders, and pays special attention to the role of concerns among the population about the local environmental situation.

Chapter 3 is devoted to assessing the risk from the perspective of those who are locally involved (risk perception). The Committee examines the various aspects that may affect the risk perception of those involved and also the consequences of this for the way in which proper communication about the risks can be achieved. In Chapter 4, the Committee discusses the assessment of the risk from the perspective of experts. The assessment of exposure and exposure's possible effects on health form a key part of this approach to the risk. This can provide an insight into how plausible it is that there is a direct relationship between particular local environmental factors and health problems. This can form the basis for deciding to what extent measures are necessary to reduce exposure.

Chapter 5 looks at how it is possible to determine whether and how local variations in health problems can be demonstrated. The Committee first discusses the pragmatic approach how to deal with reported clusters of health events and goes on to discuss the possibilities and limitations of quantitative methods for 'descriptive' epidemiological studies, based on existing data — aggregated according to location — taken from health and environmental registries. In Chapter 6, the Committee examines the criteria for performing 'etiological' epidemiological studies using health or exposure data collected at the individual level, and looks at the criteria's significance for analysing a local environmental problem.

The closing chapter provides a few guidelines that focus on government practice.

1.3 Approach

The initial memorandum for the advisory report was presented at an early stage to a consultative meeting of medical experts from municipal health services and to a few employees of the Monitoring Network for Environmental Health (a non-governmental foundation). In preparing for the advisory report, the Committee's secretary also participated in various workshops organised by this Monitoring Network on risk communication in the case of local environmental problems.

To obtain an overview of the scientific literature, a search was carried out on the following electronic databases: Medline (from 1993), Toxline (from 1981), Psychinfo (from 1989), Biosis previews (from 1993), Embase (from 1996), IAC Health (from 1976), Current Contents (from 1995) and Pascal (from 1984). The keywords used were: *local, environment, health, environmental health, risk(s), risk perception, risk communication, cluster(s), space time clustering, small area analysis and guidelines*. Some

American practical guidelines on risk communication and epidemiological studies* available on the Internet, were also used.

The following databases were also consulted to obtain an insight into specific Dutch publications on local environmental problems and how such problems are experienced as a risk: the Grey Literature in the Netherlands database (GLIN - *Grijze Literatuur in Nederland*), the Social-Sciences Literature Databank (SWL - *Sociaal-Wetenschappelijke Literatuur* databank), the Ministry of Health, Welfare and Sport's literature database (*VWS-literatuurbestand*) and the Environmental Literature Database (MLB - *MilieuLiteratuurBestand*) of the Netherlands Institute for Science Information Services (NIWI - *Nederlands Instituut voor Wetenschappelijke Informatiediensten*). In spite of the diversity of the sources consulted, it emerged that relatively few 'hard' empirical findings are as yet available from social-science research in the area of risk perception and risk communication.

* http://www.atsdr.cdc.gov/HEC/primer/html; http://atsdr1.atsdr.cdc.gov:8080/HS/gd1.html; http://www.atsdr.cdc.gov/HAC/HAGM

Chapter 2

Local environmental problems, concerns and health

Since the 1970's, many people have been concerned about the environment (SCP98). The percentage of environmental concerns reached a peak after the nuclear reactor accident at Chernobyl in 1986, and has stabilised since then at almost 85; more than 50 percent of the population is very concerned. There has been a slight reduction in concern in recent years (SCP00). Nevertheless, environmental pollution is, in the public's view, one of the major factors that affect health, after nutrition and physical movement, and more so than smoking (Com01).

At the local level, the municipal health services in the Netherlands receive several thousand questions each year from inhabitants ('informants') who are concerned about the possible effects of environmental factors on health (RIVM99b). Their questions can roughly be categorised as follows:

- What are the possible health risks of the exposure to particular local environmental factors suspected by the informant?
- Are the health complaints or disorders that the informant has observed caused by exposure to particular local environmental factors?

It emerged from a compilation of environment-related complaints at the municipal health services in 1997 that both types of questions arise in equal numbers (RIVM99b). An exposure assessment is required to answer questions of the first type; this is dealt with in Chapter 4. Questions of the second type also cover disease clusters, which resulted in the call for this advisory report; the latter questions demand cluster investiga-

tion (Chapter 5) and, if necessary, further epidemiological study (Chapter 6). Risk communication is always essential; this is discussed in Chapter 3.

2.1 Reports of local environmental and health problems in the Netherlands

Most environment-related questions and complaints that municipal health services receive each year are concerned with the indoor climate of homes and, in particular, dampness in relation to bronchial complaints (RIVM99b). Increasingly more questions are also being received about possible disease clusters that the informants link to environmental pollution outside the home. A total of 120 disease clusters were reported to municipal health services in the years 1993 to 1997, a quadrupling of the figure from ten years earlier. The majority concerned clusters of around ten cases of cancer in a single neighbourhood. Most clusters were reported by neighbourhood residents who linked them to soil pollution (45 percent) or air pollution (22 percent). A few of the reports also received national attention. For example, in the 1990's, the Health Care Inspectorate was involved in 12 'major' local environmental problems, including the cancer clusters in Weurt (Pie99) that were mentioned in Chapter 1. Before medical-environmental specialists* made their entry in 1989, the Inspectorate was involved more often out of necessity. In the period 1977-1989, the Inspectorate was involved in 74 cases, including lead emissions in Arnhem by Billiton, miscarriages in the Westland district, and cadmium in the Kempen district.

During the period from the date of its establishment in May 1994 up to December 1999, the Monitoring Network for Environmental Health (a non-governmental foundation ; see 2.2) registered almost 2200 (physical and psychosocial) complaints from more than 1800 informants, at an average rate of 300 reports per year. Most complaints concerned outdoor air pollution by industry.

By way of illustration, the Committee provided a more detailed description of the events around the cancer cluster in Weurt. This cluster became a national focus of attention in 1995.

In 1995, after years of protests about odour nuisance caused by the industrial area around Beuningen/ Nijmegen, major concerns arose in neighbouring Weurt as a result of the death from cancer of a number of young women who lived in the same street. Neighbouring residents did not believe this was a coincidence and sought the reason in, among other things, dioxin emissions from a nearby waste incineration plant.

A study by the municipal health service revealed that in Weurt, in the period 1989-1992, 50 percent more new cancer cases among men had been registered than the average figure that could be expected for

* A governmental network of twelve supraregional medical officers in environmental health has been in operation since 1989. These environmentally specialised physicians provide support to various municipal health services in carrying out their medical-environmental task.

the eastern part of the Netherlands (33 against 22). The 30 percent higher incidence of cancer among women (23 against 18 cases) was partially attributed to early discovery as a result of the introduction of a breast-cancer screening programme (GGD95). When the figures for 1993 were included in later analyses, the incidence among men turned out to be lower and the increase was no longer statistically significant. For women, there was no longer any increase in the incidence of cancer; the incidence of breast cancer was left out of the picture at that time owing to the phased introduction of population screening for breast cancer in the region, which makes geographical differences extremely difficult to interpret (Oud96).

Assuming that exposure to local environmental pollution would affect women just as much as men, the municipal health service considered it unlikely that a local environmental cause was responsible for the increased incidence among men. Moreover, the waste incineration plant in question had only gone into operation at the end of the nineteen eighties and thus, given cancer's long period of latency, the plant's dioxin emissions could not have been the reason for the emergence of the recent cases of disease.

Although 'statistically significant' clustering can occur by coincidence, external specialists suggested that the effect of other risk factors (such as smoking, occupational exposure or low socio-economic status) in Weurt could have been greater than in the eastern part of the Netherlands as a whole. This last suggestion, in particular, annoyed Weurt's residents. They interpreted a questionnaire survey containing questions about, among other things, the life style of residents, as an attempt to place the responsibility for the health problems on the residents.

This example clearly shows that epidemiological studies of the local health situation do not automatically promote the local population's trust in government. Until the municipal health service presented the cancer incidence figures, residents thought the responsible officials had shown little understanding for the emotions of those concerned (WWJ99). At the presentation, there was a change of attitude and officials promised a further investigation of the health and environmental situation. However, they were unable to make good their promise. The difficulty was that there was no simple answer that the municipal health service could give to the public's question of "Is it the environment that is making us ill?" Three months after the local authority provided the information, members of the public were still concerned and their trust in the local authority had not improved (Akk96). After this, further surveys were conducted in which local residents and environmental groups were more involved. The impression was that this possibility of participation increased residents' satisfaction with the process (Wal01).

2.2 Parties involved in local environmental and health problems

Leaving aside the polluters, the parties most involved in questions concerning the presumed effects of local environmental pollution on health are the local government, health care services and, of course, the local population.

Government and public health service

The Public Health Preventive Measures Act states that the local authority is responsible for obtaining an insight into the health situation of the local population and for advising over health aspects in administrative decisions that have consequences for the local environment (Stb90). The revised version of the Public Health Preventive Measures Act will also explicitly set out the tasks of the medical officers in environmental health. These tasks are carried out at the intermunicipal level by municipal health services. The quality of health care that municipal health services provide is monitored by the central government, in particular by the Health Care Inspectorate. The Ministry of Health, Welfare and Sport mainly has the role of creating favourable conditions. For example, it requires municipal health services to have a registered medical-environmental specialist.

The municipal health service's medical-environmental task could be described as pointing out and investigating health risks connected with environmental pollution, in order to provide well-founded advice and information (IGZ98). This also covers dealing with questions and complaints concerned with the effects of local environmental factors on health (VWS98). The municipal health service has a key role to play in answering questions on this subject for both the regional population and health care workers as well as the local authorities in the region. The municipal health service is itself responsible for promoting awareness in the region that questions and complaints can be dealt with by the municipal health service.

Curative health care

For most people, the general practitioner is the first point of contact for individual health complaints. A written questionnaire among all general practitioners in the South Kennemerland region showed that more than half of the general practitioners saw at least once a month a patient who relates complaints to environmental pollution inside or outside the home (Vri94). Likewise, half of the general practitioners indicated that they needed to have the possibility of consulting a medical officer in environmental health. There is no information on the role of other health care workers in curative health care (including community nursing workers, non-residential psychiatric health care workers, medical specialists and Comprehensive Cancer Centres) regarding answering questions about health complaints that may be related to the environment.

Residents, neighbourhood committees, environmental organisations and other interest groups

Particularly neighbourhood residents point out and report a local environmental or health problem, sometimes with the support of residents' organisations, environmental or consumer associations, welfare workers, environmental lawyers or 'science shops'. The network for health and environmental issues has also played a role since 1994. This non-governmental foundation was established because of concerns about the hazardous health effects of toxic substances and because of dissatisfaction with the way it considered authorities and specialists dealt with the problems (SMG99). With financial support from the Ministry of Housing, Spatial Planning and the Environment, the foundation registers reports it receives of health complaints that citizens believe are linked to the environment. It has also developed guidelines for better communication between citizens, government and municipal health services. The foundation also raises many problems in the media.

2.3 Health effects of environmental factors

The health effects of physical environmental factors are small in comparison with those of socio-economic and life style factors. The contribution of contaminated air, water, soil and food to the total cancer mortality figure in the Western world is estimated to be no more than four percent (Lee99).

The possible health effects of environmental factors not only apply to severe disorders such as cancer, but also to various other — more common — health problems:

- temporary harm to physical functioning or exacerbation of existing complaints, such as bronchial complaints in the case of air pollution
- nuisance, sleep disturbance or a reduction in the ability to concentrate, communicate and perform tasks
- negative perception of health, in combination with experiencing an unsafe feeling, nuisance, or stress caused by industrial activities or traffic (GR99a).

A relatively new way of grouping the different effects on health that are caused by environmental factors is to express the consequences of disorders and health complaints in terms of the number of disability adjusted life years (DALY's). The National Institute of Public Health and the Environment (RIVM) estimates that the deterioration in health that can be thus attributed to environmental pollution — also known as the burden of disease — is two to five percent of the total DALY figure for deterioration in health in the Netherlands (RIVM00b). Air pollution, noise and environmental factors in homes (dampness, radon, passive smoking) account for the largest contribution.

The current levels of air pollution caused by particulate matter and ozone in the Netherlands are estimated to account for an extra one percent of hospital admissions for bronchial disorders and a life-expectancy reduction ranging from a few days to one or two years. This premature death mainly affects elderly people (75+) (RIVM99a, RIVM00c).

Although the individual health risk posed by air pollution is relatively small, the consequences for health at the population level can be substantial (Kün00). In terms of the degree of nuisance, disease and death, air pollution is estimated to cause considerably more damage to health than soil pollution (Doo98). The language used in government policy is confusing in this respect. That is, so-called 'serious' and 'urgent' cases of soil pollution generally result in few health problems, whereas remediation measures nevertheless have to be taken. However, during 'moderate' cases of smog damage to health does occur — an increase in bronchial complaints — but no measures are taken.

The aforementioned specialists' risk estimates only partially correspond with the risk experienced or perceived by locally concerned population. Almost half of surrounding residents of a site with polluted soil turn out to be very concerned about the risks (TNO00). Fewer residents are very concerned about other environmental risk situations, such as living on a busy street, along a transport route for hazardous substances or in the vicinity of a chemical plant.

2.4 Explanations of disease clusters in the neighbourhood of local environmental pollution

A local increase in the occurrence of particular health problems, especially at the neighbourhood level, is more likely to be noticed than a decrease in occurrences and, as illustrated in the preceding paragraphs, is more likely to lead to expressions of concern. Neighbourhood residents are more likely to seek the cause of a disease cluster of this kind in soil pollution or emissions from a nearby industrial site. However, local variations in health problems are not necessarily the result of local environmental factors.

Informants are not always sufficiently aware that certain disorders or health complaints occur frequently. For example, one third of the population (16+) report 'often feeling tired' and a quarter 'fairly often being troubled by headaches' (see annex D). Around 40 percent of the population also have at least one protracted disorder; the category 'asthma, chronic bronchitis or chronic non-specific lung disease' has a relatively high score at more than 8 percent (see annex E). Sometimes, informants also count together disorders with a different cause (for example, different sorts of cancer).

If more health problems than expected do occur around a local source of environmental pollution, the Committee recognises three categories of possible explanations*:*

- coincidence
- general risk factors
- source-specific factors.

Coincidence

Natural fluctuations caused only by coincidence account for a certain variation in place and time at which particular disorders and health complaints occur among the population. This means that coincidence results in the occasional striking occurrence of similar cases of diseases in any area, such as a neighbourhood or district. This phenomenon stands out all the more when smaller areas and shorter periods are examined. In a particular area, there is even a 50 percent chance that at least one in approximately a hundred investigated disorders will occur at a statistically significant increased rate (Neu90). Therefore, the effect of coincidence alone (without any role played by a particular cause of disease) means a 'statistically significant' higher rate of cancer than can be predicted on the basis of national averages can be expected to occur in, for example, hundreds of streets, districts and villages in the Netherlands. If members of the public have a good idea of a given disorder's average rate of occurrence, then these high coincidental exceptions will be reported on the assumption that something unusual is going on. Nevertheless, many such disease clusters can be explained by coincidence (see also 5.3).

General risk factors

Besides natural variations (coincidence), local differences in general risk factors (such as demographic and socio-economic characteristics) may also be responsible for increased occurrences, or clustering, of certain health complaints or disorders in a particular area. For example, a specific age composition (aging population) or the socio-economic composition of a neighbourhood may affect the local health situation. Characteristics such as ethnicity, working conditions or life style (smoking, nutrition) may also play a role.

The lower socio-economic status of a neighbourhood around a source of contamination may, of itself, be responsible for a poor health situation in that neighbourhood, without pollution playing a role (Ell95a). In situations in which a neighbourhood with a high environmental impact is also characterised by a low socio-economic status, it is necessary to also take into account an accumulation of risk factors and possible interactions between them (see 5.3.1).

Source-specific risk factors

The Committee recognises three, not always very clearly delineated, categories of source-specific risk factors:

- physical, chemical or biological factors arising from a local environmental source
- sensory observations concerning a local environmental source
- concerns about a local environmental source.

Physical, chemical or biological environmental factors

As mentioned in 2.3, exposure to chemical, physical or biological environmental factors can lead to observable effects on health. For example, air pollution components (such as particulate matter, ozone and allergens) may cause or exacerbate bronchial complaints; exposure to noise may result in sleep disturbances or cardiovascular diseases (GR00a). Effects on health of this kind can often only be demonstrated in a large-scale survey. Health variations at the local scale are more difficult to investigate and to interpret (Mac97, Wak99).

Given current opinions on interactions between predisposition and environment, a toxic substance's effect cannot be looked at separately from a certain congenital sensitivity. That is, the degree to which a specific agent may result in undesirable effects also depends on a person's genetic constitution (GR00b). It is assumed that genetically determined differences in biotransformation may be responsible for interindividual variations in sensitivity to certain toxic substances (Wor99). For example, the rate at which an active substance is converted in the body by particular enzymes is an important determinant for the substance's — systemic — effect. Some people consider the existence of individual differences in sensitivity as a possible explanation of the finding that some people have health complaints at exposure levels that, according to current insights, cannot result in harm (Lee92). However, there is insufficient evidence to suggest that 'multiple chemical sensitivity' can be separately delineated as an identifiable clinical symptom of a disease (GR99c).

Sensory observations of environmental quality

Some people appear to be extra sensitive to sensory observations, such as odour, soot and noise, and they react to them with physical complaints (Urs97). First, some sensory stimuli — such as stimulation of the nasal nerve — may lead to immediate physical reactions (Shu92, Mac96). Second, certain physical symptoms or health complaints can be ascribed to an odour, such as that around a waste dump or factory, owing to cognitive expectations about its effect (Dal97). People often appear to assume a causal relation-

ship between a bad smell, toxicity and disease (Wil97). After all, a bad smell is a natural hazard warning (Shu92). Third, some people may experience the observations as such a nuisance that they immediately result in health complaints. For example, in a survey of health complaints and noise nuisance among residents living near a carpet factory in the Dutch town of Steenwijk, a link emerged between bronchial complaints and odour nuisance, but not between bronchial complaints and the odour that was observed (GGD99). The conclusion of an ongoing survey about living conditions conducted by Statistics Netherlands (CBS) was that various nuisance sources are related to the experience of health but the influence is stronger for odour nuisance than for noise nuisance (Ott00). The fact that concerns also play a role in this emerged from American studies carried out around waste dumps, where the relationship between the bad smell and health complaints was more pronounced in people who were concerned about the environment than in those who were unconcerned (Neu91).

Concerns about the quality of the environment

Besides sensory observations, psychosocial factors can initiate physiological — neurohormonal — processes, which in turn may result in physical complaints or disease symptoms (Doo99, Whi97). Such 'psychosomatic' reactions can be strengthened by, amongst other things, the extent of the lack of control over the exposure or the degree to which exposure is involuntary (Mac96). According to some specialists, psychosomatic complaints are unavoidable in concerns about environmental pollution and are generally of a passing nature. However, in the absence of a proper response to the complaints, they may become chronic in some people (Wes00). This occurs especially when people experience a loss of control over the situation. In the following section, the Committee further discusses the mechanisms that may form the basis for psychosomatic effects that result from concern about the quality of the (local) environment.

2.5 Concern as a risk factor

It was in the 1980's that attention was first paid to the phenomenon that concerned residents living in the vicinity of waste dumps reported physical and psychological complaints, although no increased exposure to pollutants could be demonstrated (Roh85). The number of complaints reported in questionnaire surveys appeared to be related to the degree to which the waste dump in question was seen as a health risk by residents. According to researchers, a large supposed risk provided a sufficient explanation of the higher prevalence of complaints around the waste dump when compared with the figure for a control population further away. The number of complaints was not higher among residents in the vicinity of the waste dump who did not see it as a risk.

Later publications also showed that the number of health complaints in the case of local environmental pollution was related to the degree of concern and stress (Boe98, Hav99, Lip92, Neu91). It is striking that complaint patterns in various studies display strong resemblances to each other regardless of the nature and degree of exposure to hazardous agents (Spu96, Spu97). Frequently mentioned complaints are headaches, dizziness and tiredness, for which no physical causes can generally be found.

Empirical research in the Netherlands into the health experienced by surrounding residents in two cases of soil pollution showed that residents who believed they ran a greater risk presented more health complaints than other people (Boe00a). There were also indications that especially people who felt less well reacted more sensitively to an environmental problem than others and that they also found it more difficult to put it out of their minds. After the contaminated soil had been removed, the surrounding residents were significantly less distrustful and dissatisfied with the government, less uncertain about possible health risks and had fewer health complaints.

The following psychosomatic mechanisms may provide an explanation of the occurrence or exacerbation of health problems that are not directly attributable to exposure to physical or chemical environmental factors:

- chronic stress, caused by, for example, sensory observation with a (negative) emotional significance, coupled with fear or nuisance
- symptom perception: selective observation of or increased attention to frequently occurring physical symptoms
- symptom attribution: ascribing normal physical sensations or health problems to external factors.

There is a strong relationship between these mechanisms, which comes into effect not only in suspected exposure to environmental factors but also in other stressful situations. The existence or observation of health problems, or the attribution to a supposed hazardous agent, without the effect of that agent being clear is also described as ‘nocebo’ effect, the opposite of the ‘placebo’ effect (Hab98). Fear of exposure would play an important role in this, through neurobiological stress mechanisms or otherwise.

Stress

Stress is a condition of psychological tension or pressure where certain defence mechanisms come into operation, and it may occur as the body's normal reaction to an ‘abnormal’ situation (Tuc95).

A stress reaction expresses itself as, among other things, a faster heart rate, higher blood pressure and an increase in the production of stress hormones. These expressions

disappear over time. There are indications that chronic disruption of this physiological (neurohormonal) stress system is responsible for the existence of vague physical complaints for which no organic defect can be found and which are therefore referred to as 'functional' or 'psychosomatic' complaints (Doo99).

Chronic stress can result in a variety of health complaints and disorders. The assumption is that people under stress become more susceptible to certain disorders but that the nature of the disorder depends on an individual predisposition. It seems plausible that stress is related to or contributes to the following health problems, among others: gastric complaints, insomnia, heart conditions, ischaemic heart disease, hypertension, bronchial complaints, viral infections, skin disorders and depression (GR92).

Chronic stress caused by concerns about the consequences of possible exposure to toxic substances has been frequently studied among victims and witnesses of (likely) environmental accidents or disasters. The research showed that, regardless of environmental exposure, these concerns can result in a broad range of experienced health problems. Various studies after an environmental accident or 'toxic disaster' reported not only more health complaints but also increases in visits to physicians or the use of drugs, without the increases being ascribed to an increase in physical or chemical exposure (Hav96, Hav99). It seems plausible that stress plays a role in this. For almost a year after the 'near disaster' at the Harrisburg nuclear reactor, the urine of residents in the area displayed increased stress hormone concentrations that correlated significantly with the health problems they experienced (Sch84).

Besides the traumatic experiences that distinguish some environmental calamities and disasters from more everyday local environmental problems, the following stress factors are distinguishable in the case of environmental calamities (Ber89, Hav99):

- uncertainty about the consequences of possible toxic exposure
- social stresses or (imminent) evacuation
- discrimination against 'infected' victims
- social discussion
- disturbing reports in the media.

Many of these stress factors can also occur when there are concerns about local environmental problems. Surrounding residents of a permanent local source of pollution also appear to report more health complaints.

As briefly mentioned in the preceding section, five populations of residents in the vicinity of waste dumps had more 'non-specific' health complaints (such as headaches, nausea, skin irritations and sleep disturbances) than residents in a control population further away from the waste dump (Neu91). Odour nuisance appears to have played an important role in this. People— particularly women — who lived more than three kilo-

metres from a waste dump and who were otherwise concerned about the quality of the local environment, also reported more complaints about skin irritation, eye irritation, sleep disturbance and tiredness (Lip92).

Sometimes, an innocent incident, especially when coupled with fear, uncertainty or a perceived odour, results in such acute and severe complaint patterns among large, often rapidly increasing, numbers of persons that an intoxication may be suspected (Bos97). If there are no indications of exposure to a hazardous agent, the phenomenon is referred to as 'group disease', ' epidemic hysteria' or 'mass sociogenic illness'. This refers to an acute phenomenon in a group of previously healthy individuals, for example in schools, companies or army units, who are directly or indirectly (via the media) connected with each other and who read or hear about particular clinical symptoms of a disease. In western countries, nausea, headaches, dizziness, stomach-ache, loss of consciousness and hyperventilation are especially prone to occur. The presence of ambulances, fire engines, television cameras and workers in protective clothing can reinforce the idea that the situation is serious. A characteristic of a mass sociogenic illness of this kind is that the complaints spread, as it were, through social networks. A fairly recent example was when dozens of Belgian school children became ill after drinking Coca Cola (Nem99). Toxicologically harmless, but smellable, amounts of sulphur compounds were found in some bottles. This is suspected to have contributed to the sudden emergence of non-specific health complaints, which occurred shortly after a case of dioxin contamination in the Belgian meat industry. A reduction in confidence in (the supervision of) food production probably reinforced this reaction (Pas99).

Symptom perception and attribution

Concerned people appear to observe, react to and report subtle physical sensations and symptoms before other people (Wat89, Kat98). Symptom perception of this kind could explain the fact that, according to various studies, there is an association between the number of non-specific physical complaints (such as headaches, tiredness, nausea, memory problems and insomnia) and the number of psychological complaints (Bar99). A person's psychological state (including fear, anger, and depression) may also be a major determinant in the reporting of more specific complaints. Negative emotions thus appear to be inseparably linked to experiencing and reporting shortness of breath and other bronchial symptoms (Rie97).

The experience of both normal physical sensations and health complaints is more pronounced if the person concerned thinks that they are the result of environmental exposure (Mac96). Attributing physical complaints or disease symptoms to a (generally indemonstrable) chemical-physical or biomedical cause is referred to as attribution (or

somatisation by physicians). These complaints are sometimes described as ‘medically unexplained’ or ‘functional’.

Symptom attribution is considered to be an important characteristic of the ‘functional somatic syndrome’ (Bar99). According to Barsky and Borus, self-diagnosis by the person concerned and the denial of the role of psychosocial factors are other characteristics of these complaint complexes, which may manifest in different ways in different populations. They also cite the chronic fatigue syndrome and multiple chemical sensitivity as examples of comparable complaint complexes. The aforementioned symptoms are said to often occur as a reaction to stressful situations and are then associated with fears and depressions. According to the aforementioned authors, there is a common bio-psychosocial process at the root of these complaints and it is advisable to provide the person concerned with an insight into the effect of stress factors on the symptoms experienced.

People who live in areas that are assumed to be polluted are more likely to ascribe symptoms to pollution than is the case for people who live in relatively clean areas. For example, a study in the Netherlands showed that school children in the vicinity of Amsterdam Airport Schiphol more often attributed symptoms to air pollution than children from a reference area, even though there were no differences between the two groups of children in the symptoms experienced, the objective measures of health, or the concern about air pollution (Rie99).

Not only symptoms but also certain disorders are ascribed to environmental pollution. Almost four times as many smokers (30 %) as ex-smokers (8 %) saw air pollution as the most important cause of lung cancer, even if they were convinced of the harmfulness of smoking (Cha93).

2.6 Discussion

Figure 1 uses a *triangle* to roughly show the relationship between local environmental factors, risk perception and health problems. On the one hand and given sufficiently high exposure levels, local environmental factors may directly result in health problems such as exacerbation of bronchial complaints by particulate matter (a). On the other hand, they may also result in people experiencing such factors as a risk that concerns them (b). Experiencing a high risk or perceiving a risk to be high may indirectly lead to health problems via stress mechanisms (c). These concerns may also encourage people to pay extra attention to non-specific complaints of their own (symptom perception) and to cases of disease in their environment (cluster perception). Conversely, the perception of health problems may encourage people to, correctly or incorrectly, link them to local environmental factors (‘symptom or cluster attribution’) or to over-estimate the risk of this (d). Each of these relationships may also be effected by general risk factors, such as age, socio-economic status, occupation, stress-increasing factors, etc.

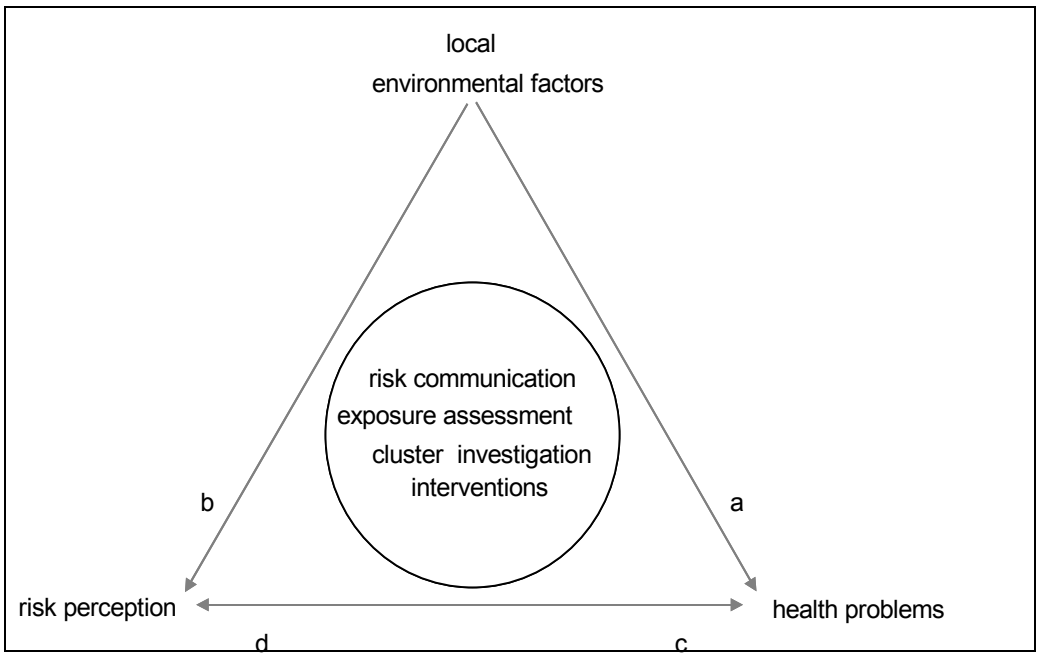

Figure 1 Relationship between local environmental factors and health

The *circle* shows the instruments that can be used, often in combination, to approach a possible relationship between exposure to local environmental factors, the risk perception of that and the health problems experienced. The instruments of risk communication, exposure assessment and cluster investigation are worked out in greater detail in the following chapters. Various interventions can also be employed to affect the aforementioned relationships. Regardless of the measures taken to reduce exposure, it may sometimes also be necessary to provide individual, and psychological, care or treatment, not only if health problems have already manifested but also if there are major concerns or stress. In this advisory report, the Committee only discusses this individual care and treatment in passing.

Chapter 3

Risk perception and risk communication

The term ‘risk’ means the likelihood that, in a certain situation, a particular degree of harm will occur. The risk assumed to exist by someone involved is sometimes referred to as the person’s opinion about the risk or perception of the risk.

In this chapter, the Committee first discusses the factors that determine the risk perception of the population concerned, and then goes on to discuss the quality, method and intensity of risk communication.

3.1 Determinants of risk perception

Since the 1980’s, considerable research has been conducted into the factors that determine the population’s risk perceptions. In most cases, this was in the form of questionnaire surveys that ascertained the degree to which assessments of the level of risk correlated with the assessment of various determinants of risk perception. It emerged that risk perception was influenced by the degree of familiarity with and controllability over the activities that influenced the risk perception (Bla95). Trust in the information source was added to this in the 1990’s. Table 1 shows the main ‘determinants’ of risk perception. Furthermore, personal factors such as attitude, sensitivity and specific fears may also affect risk perception (Sjö00).

Table 1 Important factors, influencing risk perception (Source: Bla95).

factors increasing the perceived risk	factors decreasing the perceived risk
involuntariness	voluntariness
lack of control	(supposed) control
personal disadvantages / injury	personal advantages / benefits
memorable event	ordinary event
dreaded effects (for example cancer)	not dreaded effects
technological origin	natural origin
uncertainties about risks	certainty about risks
unfamiliarity / invisibility	familiarity with the activity
moral unacceptability	moral acceptability
lack of trust in information source	trust in / credibility of information source

Various factors mentioned in the table play a role in how the risk of local environmental pollution is perceived. The surrounding residents of polluted soil or of a transmitter mast generally experience these environmental factors as involuntary and without personal benefits (Boe98). The many uncertainties about possible health risks are also characteristic of such situations. The invisibility of a factor such as radiation may also reinforce a negative opinion about the risk.

Of all determinants of risk perception, the lack of trust in the information source is considered to be one of the most important (Bla95). It is very difficult to restore trust once it has been harmed. Trust in the information source appears to depend mainly on the following characteristics of the information source (Pet96):

- expertise, knowledge of the issues
- openness
- empathy and susceptibility to emotions.

The sometimes seemingly contradictory results of scientific investigations into the risk of an environmental factor can damage the trust that concerned residents have in the authorities (Slo93). Differences of opinion between government specialists and experts who are consulted by environmental action groups receive more attention in the press and can add to the lack of trust that already exists.

Research in the Netherlands conducted among a number of 'focus groups'* showed that the distrustful attitude towards the government was partly caused by the opinion that information from the government for citizens was incomplete or provided too late (SCP00). The conflicting messages citizens received and the perceived lack of consistency in the way the government approached the environmental problem contributed to

* A focus group is a consultation group put together by researchers to discuss a current environmental subject.

the suspicions. The reliability of an information source is often assessed on the basis of the interests that are at stake.

Residents and specialists sometimes unintentionally approach a local environmental problem with rather polarised attitudes to each other: the residents are alarmed and morally incensed, and the specialists believe that the situation is not so dramatic (Boe00b). The main factors that lead to polarisation of this kind are the development of a group identity (residents as victims), the break down of mutual respect and the tendency of all those involved to see the problem dichotomously (hazard does or does not exist). These then result in the adoption of increasingly more extreme standpoints. Moreover, once alarmed, residents appear to react more sensitively to information about a risk and are also more aware of inconsistencies in the actions of the authorities.

Differences in risk perception between those who (have to) provide an opinion by virtue of their occupation and, on the other hand, the members of the public who are involved, turn out to be major obstacles in communications about the health risks of environmental pollution (Ole95). The Committee believes that knowledge about the ways in which various factors or determinants might influence risk perception could improve communication about the risk (see 3.4). However, the Committee first deals with the different opinions about risk communication and the way in which such communication can be used as an instrument for bridging the differences between the scientific perspective on the one hand and the social perspective on the other hand.

3.2 Risk communication

Two streams or 'schools' are distinguishable in risk communication (Wou99). The 'education school' assumes that concerns arise because of a lack of insight. The 'interaction school' takes the view that more support arises for decisions when the influence of the parties involved is more evenly divided. These two approaches are also known as 'technocratic' and 'democratic' risk communication:

- technocratic risk communication: primarily educational, with a lot of attention paid to putting across the message
- democratic risk communication: a process of participation of and interaction between the parties involved, with the focus on promoting mutual understanding and trust.

The Committee ideally sees risk communication as the exchange of information and opinions between individuals, groups and authorities about the nature and extent of the risk or other factors that lead to concern, opinions or reactions about risk communication messages (NRC89).

In the case of local environmental problems, the parties concerned have diverging objectives in risk communication. The Committee recognised the following objectives from the government's point of view:

- open exchanges and the provision of clear information on the various opinions about the risk
- allowing the population concerned and other interested parties to form a balanced opinion of the nature and seriousness of the identified environmental problem and of any measures to be taken (Wal98)
- promoting mutual understanding and trust between the parties in order to limit concerns and deterioration in health or to encourage action (Kas92).

It is also important to provide those involved with information about the possibilities and limitations of studies of exposure or possible effects on health (see Chapters 4, 5 and 6).

3.3 Role of various actors in communicating risks

Various social groups are involved in risk communication, each in its own way: the authorities concerned, public groups, media, health services and scientists.

The authorities

Companies and authorities have the main responsibility in terms of risk-bearing activities. Their risk assessment, often based on the relevant regulations, tends to be more optimistic than that of public groups (Wet92).

Public groups

Public groups are more likely than the authorities to point more to the many scientific uncertainties, which they use to mobilise the media and political parties in order to influence decision-making processes (Wet92).

Media

Members of the public are mainly dependent on the news media for information (Gut96). Analyses of press and television reporting on approximately 600 clusters of health events in the United States showed that the media mainly stress drama, personal feelings, contradictory information, the issue of blame and political symbolism (Gre90). The media also make a selection, focusing strongly on local environmental problems

with unknown, uncontrollable or potentially ‘catastrophic’ risks (Slo86). Various researchers believe that the media play a major role in reinforcing negative opinions about the risk, sometimes on account of the public's loss of trust in the authorities and social organisations (Dij99, Fro97, Gut96, Ren92). On the other hand, the media can play a positive role in the communication process, provided that they are, for example, informed in good time about the results of research (Han90). A good and trusting relationship between researchers and journalists is essential for this.

Health services

One of the tasks of (municipal) public health services is to answer questions about the risks presented by local environmental factors (see 2.2). Members of the public do not, though, always see the municipal health service as a reliable professional organisation (Gut99). Trust and credibility demand expertise, openness and empathy (Pet96). The role of physicians who specialise in medical-environmental science is also of major importance, and is also stressed in other countries outside the Netherlands (Spa93).

Scientists

Scientists derive their credibility from their expertise and independent status. There are various viewpoints about their independence. The public and media particularly often tend to have little trust in reports on studies commissioned by the government or a company (Köb99). This lack of trust is fed by delays in reports and by the fact that reports often employ difficult-to-understand terminology.

3.4 Risk communication in line with determinants of risk perception

Only a few of the determinants of the risk perception mentioned in 3.1 have been examined in an experimental research set-up to determine whether influencing them — through, for example, risk communication — also influences the opinion about the risk.

Comparison with more familiar risks

Greater clarity about environmental risks can sometimes be provided by comparing them with more well-known and familiar risks. From the point of view of communication, risk comparison is most advisable if it concerns related agents, different agents with the same effects, different agents to which people are exposed in a comparable way and different sources of the same agent (CRA97). The risks should also preferably be compared with other risks that have the same characteristics, such as involuntariness

(NRC89). For example, it is better to compare a risk that the population experiences as being uncontrollable, such as bronchial disorders caused by air pollution, with the risk of passive smoking rather than with that of active smoking (Doo98).

Empowerment and public participation

The assumed control or lack of control over the situation can be influenced by taking and maintaining risk management measures or by giving advice on how to act in order to limit exposure. Facilitating empowerment enables those involved to gain mastery over the situation (Ric95).

The involvement of residents in the exposure assessment and cluster investigation at an early stage and on an equal basis (resident, citizen or public participation) enables involved residents not only to regain their influence over their home environment but may also enable the restoration of damaged trust. Trust in the credibility of concerned specialists and the authorities appears to be one of the most important determinants of the opinions about the risk to the public.

Although public participation cannot settle all the — sometimes deep-rooted — conflicts between the public and the authorities, it can improve mutual trust between them (Slo93, Row94, Fis95). The commencement of an early dialogue between the different parties will contribute to the communication's effectiveness (Ole95). The importance of public participation was stressed by the Third European Ministers Conference on the Environment, in London (WHO99) and in the Seveso II directive for companies that present a risk (Wal99).

As early as 1984, in the Netherlands, on the grounds of a study commissioned by the Ministry of Housing, Spatial Planning and the Environment into the psychosocial aspects of a number of cases of soil pollution, public participation was recommended for inclusion in the project approach to soil pollution (Baa84). One of the conclusions of that study was that action taken by the government stirred up more emotions than the actual pollution and that an active communication policy proved to result in less distrust.

Within the scope of this, it is considered important to publish (preferably under the editorship of a consumer organisation, and with government backing) ‘guidelines for citizens’ on risks, risk communication and public participation, (NRC89). In the Netherlands, the guidelines for public participation within the scope of the ‘Soil Remediation Policy Renewal’ project provide an example. These were commissioned by the Ministry of Housing, Spatial Planning and the Environment and drawn up by the Dutch Toxin-free Foundation (part of the Nature and Environment Foundation) and the Dutch Centre for Civic Education. Consultations were also held with many interested parties, including resident groups and officials. With financial support from the Ministry of Housing, Spatial Planning and the Environment, and in cooperation with representatives of social

organisations and municipal health services, the Monitoring Network for Environmental Health also made recommendations for public participation in health problems in relation to some specific local environmental problems.

3.5 Guidelines for risk communication

When there are concerns, it is generally the speed at which information is provided that is important for removing uncertainties as far as possible and preventing concerns from growing (CDC90). Rowan adopts just one basic rule for adequate risk communication: he believes that being honest is the only way to sound credible (Row94).

Little research has been conducted into the effectiveness of risk communication (Gut96). Experimental research in which, say, half the population is involved in a genuine situation in the risk communication process while the other half is kept away from it is impossible, owing to practical and ethical limitations. It appears from the scarce data available that figure-based information on the size of the risk is not very effective (Ren92).

The US Department of Health & Human Services used 10 studies in attempt to determine the effectiveness of Covello's guidelines for risk communication*. Public participation and cooperation with authorities that are considered reliable proved to be the most effective guidelines, while careful planning and evaluation were the least effective (Cov88, EHPC94).

The Committee subscribes to the following guidelines for risk communication, which were drawn up on the basis of the available insights (OUF97). They especially apply to the government in interaction with the public as well as the media:

- take public indignation and concerns seriously, by listening, responding properly to emotions, demonstrating involvement, establishing informal contact and going into the reasons for indignation and concerns
- involve the public in decisions at an early stage
- pay attention to acquiring trust and credibility, by being expert, keeping promises, not disguising inconsistencies, announcing study results immediately and providing an insight into the decision-making process
- pay attention to the manner of presentation (avoid jargon)
- provide the best possible explanation of the existing risks by:
  - providing insight into exposure routes and the method, results and consequences of exposure assessment

* *Seven cardinal rules*: 1. Accept and involve the public as a partner. 2. Plan carefully and evaluate your efforts. 3. Listen to the public's specific concerns. 4. Be honest, frank, and open. 5. Work with other credible sources. 6. Meet the needs of the media. 7. Speak clearly and with compassion.

- only comparing risks with similar risks
- making recommendations on what action to take and keeping possibilities for contact open.

These guidelines are mainly based on practical experience and have only been scientifically substantiated to a limited degree (Wou99).

3.6 Discussion

People may assess or experience the health risks of a particular activity differently, depending on the nature of the situation, the weight attributed to available information and the interests that are at stake. Quantitative aspects, such as the anticipated number of cases of disease or death, predominate among many specialists. Among citizens and interest groups that feel threatened, opinions about the risk are largely determined by other aspects, such as the credibility of the information source and the lack of familiarity with, or the lack of control over, the risk. Good risk communication can help provide greater mutual insight into the perceived risks.

A situation can sometimes be made clearer by comparing environmental risks with familiar, but otherwise similar, risks. In doing so, it is important not to trivialise the risk that concerns the public. The main aim is to show the risks in a realistic perspective. The Committee stresses that comparing environmental risks with dissimilar risks, such as accidents, may have the reverse effect.

In practice, 'communication' about risks remains rather limited to the one-sided provision of 'information' about risks. The Committee believes that risk communication should involve listening to and interacting with the citizens concerned. The Committee therefore describes risk communication as the exchange of information and opinions between individuals, groups and authorities about the nature and extent of a risk. This enables all the parties involved to make a better assessment of the risk on the basis of the information that is relevant to them and to do everything possible to limit the consequences of the situation. Although the positive effects have not been scientifically proven, the Committee sees risk communication, especially in the form of public participation, as a necessary part of the approach to local environmental problems. However, there is little point (and the effect may even be the reverse of what was intended) in involving people, if nothing is done with their comments and opinions.

In conclusion, the Committee believes that guidelines for risk communication and public participation may be useful in approaching local environmental problems, even if hardly any research has been done to indicate the extent to which these guidelines work in practice. The Committee also believes that risk communication is not only worthwhile for getting a hazardous situation under control but that sufficient space should also

be provided for communication with and participation by citizens in an anticipatory environmental and health policy. The Committee thinks this could establish the basis for a better relationship based on trust between the authorities and the public and would possibly prevent many concerns from arising.

Chapter 4

Exposure assessment

This chapter is devoted to the risk approach from the perspective of the authorities concerned, based on current scientific, risk-assessment methods. There is generally a distinction between risk assessment and risk management (GR96). A risk assessment forms the basis for the concerned authorities' determination of the extent to which the exposure in question requires measures or rules of conduct (risk management).

4.1 Risk assessment: exposure and risk characterisation

The purpose of risk assessment is to determine the nature, seriousness and extent of potential health effects in a particular population group.

A risk assessment consists of the following steps (GR95, GR96):

- identification of the hazardous factors (physical or chemical agents, or stress factors) that are involved
- examination of exposure-effect relationships on the basis of data from the toxicological and epidemiological literature
- determination of the degree of exposure (also known as exposure assessment or characterisation)
- provision of a description of the health risk on the basis of a comparison of the exposure with known exposure-effect relationships (risk characterisation).

A risk assessment is not just a technical-scientific, but also a social process. As indicated in Chapter 3, it is also necessary to take into account the point of view and knowledge of

the interested parties through the participation of all those involved and the provision of feedback to them (Slo99, Ste96). Given that the (lack of) trust in the authorities concerned plays a major role in the risk perception of those involved, transparency is essential during the entire process of risk assessment and management. Therefore, it is important right from the first step of the risk assessment to properly describe and delineate the problem of those concerned: Which environmental factors play a role in the case in question? It is also advisable in the final step of risk assessment to check the calculated risk described in a risk characterisation against characteristics that are of value to those concerned (GR96). A risk characterisation can be in many forms, including, for example, the likelihood of disease or death, the loss of life expectancy or health, the perceived quality of the environment, or the nuisance experienced. The risk characterisation should preferably also include information about the degree of uncertainty and sometimes includes a comparison with other risks.

The most scientific part of the risk assessment is the determination and assessment of the exposure. The following paragraph is dedicated to this.

4.2 Determining and assessing exposure

In principle, there are three methods for determining human exposure to physical or chemical factors: making an estimation of the possible exposure routes by visiting the site, measuring, and modelling (Bru96).

Given the diversity and complexity involved in determining exposure, a combination of exposure modelling and measurement is generally necessary. For the present purposes, the Committee only provides a brief description of some general aspects of, and criteria for determining chemical exposure in particular. The Committee points out that exposure measurement does not always provide the best measure in terms of health risks. For example, a measurement made today often only provides a poor indication of past exposure. Therefore, an exposure estimate (for example, the calculated field strength based on the distance from homes to a particular power line) may provide a better measure of the risk of long-term exposure than the exposure measured at a particular time.

4.2.1 Methodology

In principle, both external and internal exposure can be determined.

Risk assessment based on external exposure

A risk assessment based on external exposure involves the following steps:

- determination of the concentration of hazardous agents in relevant 'contact media', namely: water, air, soil or crops
- estimation of the amount of the contact media consumed
- calculation of the total intake or inhalation of the concerned agents
- comparison of total intake or of inhalatory exposure with health-based recommended exposure limits and information on exposure-effect relationships.

In recent years, more use has been made of real case scenarios (based on realistic assumptions for the degree of exposure and as an alternative or in combination with worst case scenario's) for the determination of external exposure (Pau90). The exposure assessment also has to take into account background exposure (nutrition, smoking, indoor air) and exposure as a result of work and hobbies.

If the calculated intake from a specific local environmental source leads to a demonstrable increase in the body burden or possible adverse effects on health being expected, then it may be advisable to determine the internal level of exposure. This may also be advisable if the estimated potential health damage is, owing to a lack of information, not completely reliable.

Risk assessment based on internal exposure

In risk assessments based on internal exposure (body burden), chemical substances, their metabolites or their early, specific biochemical effects are measured in body fluids, body tissues or excreta (Zie78). Familiar examples are assessments of lead concentrations in blood, cadmium in urine, benzene in exhaled air, and dioxins in breast milk. An assessment of internal exposure includes a concentration determination in relevant substrates of the body, followed by a comparison with known exposure-effect relationships.

Blood or urine analyses are sometimes requested when there are public concerns about local environmental problems. Although internal exposure is generally better than external exposure for predicting effects on health, the method is also subject to some sampling, technical-analysis and ethical limitations. Analyses of this kind do not therefore automatically provide the best answer to questions about the possible risks presented by local environmental factors. Therefore, the Committee first discusses the conditions that any such study must generally satisfy.

4.2.2 Conditions for investigating internal exposure

It is advisable to adopt the following criteria when considering the degree to which an investigation of internal exposure is worthwhile, (Bru96, Pie83, Ver95, Zie78):

- the internal exposure 'indicator' must be sufficiently specific for the external source(s)
- sufficient knowledge must be available about the (systemic) effects of the exposure in question on humans and especially about reliable exposure-effect relationships
- sufficient knowledge must be available about toxicokinetics: uptake, metabolism and accumulation
- the time and duration of sampling, the exposure profile and the nature of the effects (acute or chronic) must be matched to each other
- the biological half-life must be sufficient for the exposure indicator to still be demonstrated
- the exposure indicator must be present in easily accessible human tissues
- reliable and convenient sampling and analytical methods (with relevant detection range) must be available
- obtaining, transporting or storing the substances may not lead to contamination, absorption or conversion
- proper reference data, or a proper control group, must be available.

Other aspects that have to be taken into account are:
- feasibility
- support for participation by those involved
- the possibility of intervention: environmental measures, rules of conduct, individual care or treatment
- a positive balance of the pros and cons for the individual or group: an acceptable 'cost-benefit' ratio.

Measuring internal exposure is not always beneficial for those involved. In particular, the interpretation of individual measurement results may have adverse consequences for participants in the investigation. After all, a once-only determination need not reflect the relevant time-average exposure, which means people will either be unnecessarily emotionally troubled or wrongly reassured. When considering conducting an investigation of this kind, the disadvantages should therefore also be balanced against the intended benefits: the possibility of reassurance when no exposure or effect is demonstrated. From this point of view, in accordance with legislation and regulations and, if necessary, in consultation with a medical-ethics committee, it is also important to have clarity about the extent to which those concerned should be informed of or given an opportunity to examine their individual results. Clarity about the criteria for a follow-up investigation, care or treatment is also essential.

4.2.3 *Exposure assessment*

Health-based recommended exposure limits and background information on exposure-effect relationships (including from epidemiological studies) play a major role when assessing exposure. The Acceptable Daily Intake (ADI) and the Maximum Permissible Concentration (MPC) in air are examples of recommended exposure limits below which no adverse effects on health are expected on the basis of current knowledge. Once having established that there has been no exposure in excess of health-based recommended exposure limits, it may generally be assumed that the exposure in question will not result in damage to health. However, when working out these limits, specific risk groups or possible effects on subsequent generations must be taken into account, especially if the people who may have suffered exposure belong to a sensitive group. Moreover, the interpretation should, as far as possible, take into account the possibility that simultaneous exposure to different agents with a similar effect may well result in an effect even if the specified limit has not been exceeded for any of the single agents concerned.

If exposure in excess of health-based recommended exposure limits has occurred, then the extent to which damage to health can be expected must be determined, given the size and duration of the exposure. It is important in the interpretation to also take into account that, because particular safety factors are used, there is often a considerable margin ('grey area') between the health-based recommended exposure limits and the exposure level at which adverse effects may occur. If health-based recommended exposure limits are exceeded, measures should be considered to reduce the exposure. The urgency of the measures depends upon the duration and degree of exposure in excess of the limit as well as upon the adopted safety factors.

4.2.4 *Examples of exposure assessment*

A few examples are provided below of situations in which an exposure assessment proved advisable.

Example 1: Lead levels in children living in the Stein port area

Following soil contamination with lead in the municipality of Stein, a survey was carried out to determine lead levels in the blood of children aged 3-12 (RIVM84). The lead levels in children who lived in the most contaminated port area were generally higher than lead levels in children living in less contaminated areas in Stein. These levels were also higher than that of children living in other residential areas elsewhere in the Netherlands. In consultation with the general practitioner and parents, the investigation was continued on an individual basis in six children whose blood contained lead concentrations in excess of what was then considered the health-based permissible limit (300 μg/l).

Example 2: Harbour sludge under residential area Steendijkpolder

In 1983, 800 homes and various schools were built at the Steendijkpolder, in Maassluis, on a four-metre thick layer of harbour sludge from the Rijnmond area (Wij88). Various solvents, tar-like compounds, pesticides and heavy metals were found in the sludge. Investigation of all the relevant environmental compartments showed that soil ingestion through hand-mouth contact by toddlers was the main exposure route. According to a worst-case model, the intake of persistent pesticides (drins) was double the Acceptable Daily Intake (ADI). Owing to a safety factor of 100 in the ADI, no demonstrable damage to health was expected. It was thus recommended that no investigation of the body burden or further epidemiological study had to be conducted.

Example 3: Living around a waste dump containing chemical waste in Volgermeerpolder

In the 1950's and 1960's, approximately 2,000 tonnes of chemical waste were dumped on a waste dump in the Volgermeerpolder in Broek in Waterland (Wij90). On the basis of the concentrations of chlorinated hydrocarbons, including dioxins, in surface water samples, channel bed sludge, soil, flora and fauna, Amsterdam's municipal health service concluded in 1983 that the exposure of surrounding residents was probably below health-based recommended exposure limits (among which the ADI). A medical examination was therefore not considered worthwhile.

Example 4: Vegetable gardens on cadmium-polluted soil in the Kempen district

In the Kempen district, the soil in a 350 km^2 area is polluted with cadmium from the emissions of local metal working companies (Cop90). This resulted in relatively high cadmium concentrations being found in locally-grown vegetables. The National Institute of Public Health and the Environment (RIVM) calculated that the exposure of the local population was consequently close to the ADI, excluding cadmium exposure caused by smoking (Kre90). Partly because the limit above which health effects are possible is only a little higher than the ADI, various epidemiological studies, including urine analyses, were conducted. These showed that cadmium levels in the local population were high when compared with those of a control population and that there were indications of reduced kidney functioning. On the basis of this, the Ministry of Housing, Spatial Planning and the Environment provided funds for the remediation of the contaminated gardens.

Example 5: Living above dry cleaning launderettes

The Maximum Permissible Concentration (MPC) in air for life-long exposure of the general public to perchloroethylene (250 $\mu g/m^3$) is exceeded in many homes above cleaning launderettes (RIVM00a). The highest concentration discovered was 17,500 $\mu g/m^3$. The lowest level at which effects were demonstrated at the population level in the working situation (indications for reduced kidney functioning) is an order of magnitude higher (102,000 $\mu g/m^3$). The National Institute of Public Health and the Environment (RIVM) therefore considered that individual medical examinations were not worthwhile in view of the concentrations found in homes. As the figure exceeded MPC, insulation or measures at the source were required, with the urgency of the measures depending upon the duration and degree of exposure in excess of the limit.

4.3 Discussion

According to the Committee, it is generally advisable to first assess external exposure in cases of environmental problems. Experience has shown that this is often sufficient. After all, if this exposure exceeds health-based recommended exposure limits, it is a criterion for considering taking measures to reduce exposure. The urgency of the measures depends on the exposure level at which adverse effects are expected.

If external exposure exceeds background exposure so much that a demonstrable increase in body burden or damage to health is expected, then there should be an assessment of the advisability of measuring internal exposure (body burden) by means of, for example, blood or urine analyses. This can also be considered if external exposure assessment does not provide sufficient information for making a reliable estimate of the potential damage to health. Given the possible technical measurement and ethical limitations, the Committee thinks critical consideration is called for when setting up a study of the body burden. It recommends that a study of this kind should only be conducted after considering the criteria stated in 4.2.2, in consultation with specialists in this field.

In situations in which there is no demonstrable exposure, it is only occasionally necessary to consider taking blood or urine samples in order to anticipate any future questions or concerns about possible exposure. This could, for example, apply in the case of a definite suspicion of exposure to a chemical agent that cannot be demonstrated at the time. The Committee also considers it necessary in such cases to bring in specialist expertise.

In accordance with the discussion in Chapter 3, it is extremely important to communicate properly with those involved and, if necessary, with local general practitioners about an exposure assessment's purpose, possibilities and limitations, especially if these are based on a study of the body burden.

Chapter 5

Cluster investigation

The degree to which epidemiological studies may be useful in assessing concerns about disease clusters* in relation to local environmental factors was a key part of the assignment to produce this advisory report. As mentioned in chapter 2, this question also arises among many of those concerned; they often attribute a cluster of diseases to a common cause in the local environment, such as a local environmental problem (Huu95).

Disease clusters may lead to many concerns at the location. Concerns are likely to increase, if there is no proper response. Therefore, for this reason too, it is 'good public health practice' for local services, such as the municipal health service, to respond quickly and properly. The main objective is to assess the plausibility of any relationship to local environmental factors. The results of the assessment can form the basis for taking measures to limit exposure or to assess the necessity of a more detailed investigation. Some aspects of this have more in common with incident management than with a study (Qua99).

In this chapter, the Committee discusses the necessity of investigating such disease clusters and the conditions under which the investigation should be conducted. It does not focus on reports relating to the nuisance or complaints caused by the source of a particular noise, odour or substance, if no health problems are associated with it.

* A disease cluster is an unusually high number of similar cases of disease in a given area, period or population (Dri89).

5.1 Dutch cluster approach

Working according to some American guidelines for responding to disease clusters, a stepwise approach was developed in the Netherlands for the municipal health service in 1989 (Dri89). The method was adjusted in 1996 on the basis of new references and an evaluation made by municipal health service workers in the province of South Holland (Dri96). Almost all the participating municipal health service workers have indicated that they use the 'stepwise approach' (RIVM99b).

In the Dutch 'triple' approach, it is essential to distinguish between three tracks: the health, environmental and relationship track, in which the following sub-questions are investigated (Dri96):

- health track: to what degree there are indications of an increased number of health events or complaints?
- environmental track: to what degree there is or was increased exposure to environmental contaminants, via air, water, soil or crops?
- relationship track: how plausible it is that the exposure to local environmental factors could bring about the effects on health that have been identified?

Each of the sub-questions can be investigated in three phases, namely (see figure 2):

1 orientation phase
2 (qualitative) verification phase
3 (quantitative) analysis phase.

Section 5.2 provides a description of the different phases, which cannot always be strictly separated in practice and are not always necessary for all the tracks.

In line with the import of chapter 3, proper communication with those involved is important in all the phases and tracks (Dri99). The importance of proper risk communication in cluster investigation is also stressed in international guidelines for cluster investigation and it is recommended that residents and their representatives should be involved at an early stage in considering whether further investigation is advisable and feasible (ATSDR96, CDC90). Therefore, figure 2 includes a 'communication track'. Risk communication starts with the first telephone call, in which the informant's problem is explored. In the verification phase, a further personal conversation is not only held to gather information on cases of disease, but also to pay attention to the risk perception and concerns of the informant(s); this forms the basis for issuing information about the 'normal' occurrence and possible causes of the disorder concerned, the possibilities of exposure to local environmental factors and any health risks this involves.

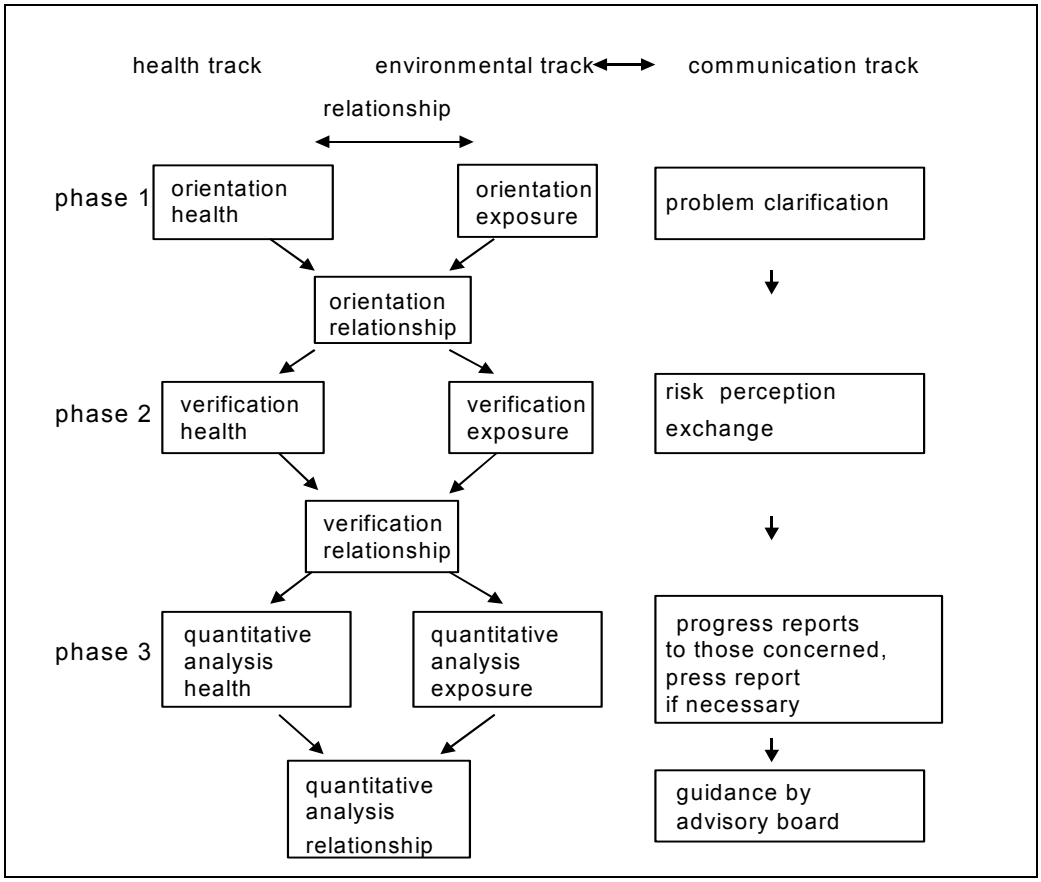

Figure 2 Flow chart of the stepwise approach to a cluster investigation.

It is also recommended that all interested parties should be involved in the quantitative analysis phase, which is sometimes necessary. Especially if a further epidemiological study among the local population is being considered of the relationship between the environmental exposure and the health problems (see chapter 6), it is advisable to form an 'advisory board', in which the pros and cons of the various investigative methods can be discussed. Examples of etiological epidemiological studies in the Netherlands, in which advisory boards were formed with representatives of (organisations of) surrounding residents, are the Health Impact Assessment Schiphol and the epidemiological study of the occurrence of health complaints after the Bijlmermeer air crash disaster.

An evaluation study among all municipal health services in the Netherlands into how disease clusters were dealt with in the period from 1993 to 1997 showed that in most cases of cluster reports, the cluster investigation was terminated after the verification phase because the reported cluster could be satisfactorily explained, for example

because a cancer cluster could be attributed to the aging local population (RIVM99b). Only seven percent of the 120 disease clusters that those concerned associated with environmental pollution could be finally confirmed. Environmental exposure could only be demonstrated in fewer than two percent of the reports. Because of this, the municipal health service did not consider further investigation into a causal relationship between the disorders and a local environmental factor was necessary for any of the reports. Similar findings were reported in the United States (Smi93). Although cluster reports are practically always a reflection of concerns about local environmental factors, in the United States it emerged that it was only occasionally plausible that an environmental factor had a causal role (CDC90).

According to the municipal health service workers consulted, approximately three out of four informants were satisfied with the results of the investigation; the dissatisfaction of the remaining 25 percent was apparently mainly connected with the continued presence of the source of the pollution (RIVM99b). If problems occurred, they were mainly in the area of communication. The largest source of dissatisfaction for municipal health service workers themselves was the lack of time and capacity for investigation and risk communication. The investigators concluded that the stepwise approach to disease clusters was a useful instrument but that the municipal health services would have to pay more attention to risk communication.

5.2 Cluster investigation in three phases

In this section, the Committee briefly explains the stepwise approach introduced in 5.1 for responding to reports of local clusters of health events. A more detailed explanation is provided in the chapter on Disease Clusters, in the Outdoor Environment Manual (*Handboek Buitenmilieu*) for municipal health services (Dri96). As a supplement to that chapter, a working group of municipal health service workers recently developed brief guidelines for the verification of cancer clusters, in which these issues are worked out in a practical way in the form of checklists (GGD01).

5.2.1 Orientation (phase 1)

After the report, general background information is gathered in the first phase about:

- the normal occurrence of the health events concerned (health track)
- the possibilities of exposure, by means of a site visit (environmental track)
- the biological plausibility of the causal relationship, on the basis of a literature study (relationship track).

Gathering this information can be seen as preparation for personal contacts in the verification phase with those concerned. No further verification need take place, if the informant is left completely satisfied after receiving information by telephone or in writing and there are no public concerns about a possible relationship to local environmental factors.

5.2.2 *Verification (phase 2)*

The second, qualitative phase of the cluster investigation is that of compiling and interpreting data on:

- the nature and number of disorders or health complaints known to the informant, to enable a rough comparison with the anticipated number (health track)
- the nature of the local environmental pollution assumed to exist by the informant and verified by the local or provincial authority (environmental track)
- sequentiality of the time relationship between, on the one hand, the exposure experienced and, on the other disorders and health complaints (relationship track).

Owing to the compilatory character of this phase, formal statistical analysis is not an issue here. The persons concerned generally benefit more from a classification of the facts and an explanation that addresses their concerns of the mechanisms of exposure and the incidence and prevalence of the diseases in question (Coe98). As also stated in 5.1, risk communication with the residents concerned and their participation are more important in this phase.

Working in this way, with the aid of the collected data, it is possible to make a rough calculation in which the reported number of cases of disease or health complaints in the population concerned is roughly compared with the number that could be expected, on the basis of general population characteristics, such as age and the number of inhabitants. If the number of reported health problems does not exceed the expected number and there are no indications of increased exposure to the suspected environmental factors, the investigation can be closed after the verification phase. This has thus far been the case for most cluster reports (RIVM99b).

However, there are grounds for switching to the quantitative analysis phase, if more health problems are reported in the population group than expected or if there are indications of increased exposure to local environmental factors. This may also be the case when there are remaining doubts or concerns about health or exposure.

A brief report is drawn up on the basis of the findings, which is then explained to the informant, if possible in person. The report should result in recommendations about the advisability or necessity of a further investigation of the exposure or cluster.

5.2.3 *Quantitative analysis (phase 3)*

The third, quantitative phase of the stepwise approach covers:

- calculating the — age-standardised — incidence or prevalence compared to a reference population, or advanced form of 'cluster analysis' (health track)
- determining exposure, if necessary on the basis of additional exposure measurements, and comparison with health-based recommended exposure limits and known exposure-effect relationships, the so-called exposure and risk characterisation and assessment (environmental track)
- etiological environmental epidemiological study (relationship track).

At this point, the Committee first discusses the health, environmental and relationship track of the quantitative analysis phase of the cluster investigation, before going on to discuss the health track.

Health track: descriptive epidemiological studies

On the basis of an analysis of all the available and often routinely collected disease and complaint records, a determination is made of the degree to which the disorders or complaints in the population concerned occur more often than in well comparable reference or control population, taking into account the differences in age composition (see 5.3).

Environmental track: exposure assessment

In this phase, the environmental track consists of a risk assessment, in which exposure is determined and assessed on the basis of health-based recommended exposure limits and known exposure-effect relationships (see Chapter 4).

If it emerges that no exposure has taken place above health-based recommended exposure limits, including those that apply to risk groups, it is unlikely that the health events concerned are attributable to the suspected environmental factor. The correct period must also be taken into account, given the latency period of the disorder concerned.

If the estimated exposure is higher than the health-based permissible level, it is advisable to recommend measures to reduce exposure. As argued by Rothman (Rot90) in particular, measures taken at the pollution's source may be more important to the public than further investigation into a possible causal relationship between the pollution and the health problems. Moreover, it is easier to substantiate measures on the grounds

of possible standard levels that have been exceeded than it is on the grounds of epidemiological studies.

Relationship track: etiological epidemiological study

An investigation of the supposed cause-effect relationship would only be advisable, if the environmental track led to indications of health-based relevant exposure and clearly more health events occurred than would be expected.

A causal relationship can only be made plausible by means of a further epidemiological study, with data collected on the health problems, the expected exposure and all other risk factors at the individual level. Epidemiological studies of this kind are extremely time consuming and labour intensive, and, if they are to provide the required answers, they are only advisable if numerous conditions are met (see Chapter 6).

5.3 Quantitative cluster investigation

Descriptive epidemiological studies, based on already available health data at the geographically aggregated level are known as ‘small area health statistics’: i.e. the analysis of health data with a high spatial resolution. Ideally, the data will be available from existing records at the individual level, but for reasons of privacy, the postcode level is usually the most suitable level. Descriptive epidemiological studies are often less labour intensive than etiological epidemiological studies with data collected at the individual level.

The most traditional and still commonly used method for comparing a properly defined, exposed study population with a proper reference or control population is based on calculating standardised mortality or morbidity ratios (SMRs) (Gol00). In principle, studies of this kind can be readily conducted by the municipal health service or by health-record administrators, such as the Comprehensive Cancer Centres. Examples in the Netherlands are the studies of the occurrence of cancer in Weurt in the vicinity of an industrial site in Nijmegen; in the vicinity of a high-tension line in Odijk; and around Amsterdam Airport Schiphol.

When SMRs are determined at the postcode level for relatively infrequently occurring disorders, further data processing is usually necessary to correct for coincidental fluctuations. This requires techniques from spatial statistics, such as ‘Bayesian smoothing’, which require special expertise.

If an increased SMR is discovered in a suspect area, an investigation of possible risk factors or monitoring of the disorder in question may be worthwhile. Sometimes it is advisable to study the disorder’s occurrence in comparable exposure situations elsewhere as well. The boundary definition in place and time can then primarily be chosen

on the basis of the exposure, in order to avoid bias in the study results (see 5.3.1). An example of this was an investigation of the occurrence of cancer around all the waste incineration plants in England, after an increased number of cancer cases was noted around a specific waste incineration plant (Ell92). Another example was the study of the occurrence of cancer around twenty radio and television transmitters in England, as a result of a reported cancer cluster around one transmitter (Dol97).

The Committee has also considered advanced cluster analysis methods, which can be divided into: adjacency methods, distance of nearest neighbour methods, cell count or fixed cell methods and specific methods for cluster analysis around point sources (Her98). However, the Committee believes that most methods make high requirements on the expertise of prospective users and are in general too complex for decentral use. Moreover, because of a lack of consensus about the answer to the question of which methods can be most appropriately used in which situations, the Committee does not provide a detailed description.

5.3.1 Limitations of quantitative cluster investigation

Descriptive epidemiological studies are subject to various limitations, especially when conducted in connection with the occurrence of a an already noticed cluster.

Practical limitations

Owing to privacy legislation, individual disease data can no longer simply be supplied at an aggregated level (postcode, neighbourhood or municipal level) that matches the level of the local exposure.

Methodological pitfalls

If a cluster of health problems is ascertained in a particular area, it does not necessarily indicate an effect of local environmental exposure (see also 2.4). From the epidemiological point of view, various other explanations are possible, which are briefly explained below and which should be taken into account when interpreting the investigation's findings:

- coincidence
- bias
- confounding by other location-based risk factors.

Coincidence

In many descriptive epidemiological studies, the aim is to draw a conclusion about the extent to which the possibly increased occurrence of a particular disorder can be explained by either coincidence or a particular cause. A statistical test is then used to estimate whether the difference between the number of health events discovered and the expected number is so high that a particular cause of the disease is likely. If no difference is expected beforehand and with the usual significance threshold of five percent, there is by definition a five-percent likelihood that a 'statistically significant' difference will be found that can be attributed to coincidence. If several statistical tests ('multiple comparisons') are made for different disorders or in different areas, a 'statistically significant' different number of health events will be attributable to coincidence in one in twenty checks. As mentioned in the introduction to 5.3, specific correction techniques are available in spatial statistics for this, such as Bayesian smoothing.

Likewise, in practice, to assess a cluster report, statistical checks are used to determine whether a detected large number of health events can be attributed to coincidence. However, in a detected cluster, the results of a statistical test are unreliable and investigators often incorrectly conclude that something unusual is occurring. In such cases, the conditions for a valid statistical test have not been fulfilled. After all, the occurrence of the health problems was (possibly unconsciously) compared with what is normal in a particular area, after which it is particularly an increase that tend to be noticed and reported. This phenomenon, which is 'hidden' from the investigator, is referred to as the 'occult multiple comparison' problem. This means that even if a statistically significant cluster exists, it is not generally possible to draw conclusions about whether an increased incidence or prevalence is a coincidence.

Bias

The epidemiological effect measure can be biased in three ways, namely: through selection bias, information bias or confounding (Rot98). The last of these is distinguished from the first two because it is generally possible to adjust for it in the statistical analysis. Therefore, the Committee discusses the term confounding apart.

Selection bias may occur because of the way in which the study population is selected. Leaving aside the factor of coincidence, selection bias is one of the main limitations in a quantitative study of previously detected clusters; after all, it is only afterwards *(post hoc)* that the study design is determined and that the location, time, disorder and population characteristics are defined (Ell95b). An example is the problem that is referred to in the American literature as 'Texas sharp shooting': shoot first and draw the target later. With this, the place or time of a cluster is delineated by the reports and not

by a particular zone determined on biological grounds around the possible causal factor (Rot90). In this situation, statistical tests will often incorrectly result in statistically 'significant' findings. To prevent selection bias, it is sometimes advisable to also conduct an investigation elsewhere, in comparable exposure situations. The boundary definition in place and time can then be chosen beforehand (*a priori*), on the basis of the exposure (see introduction 5.3).

Information bias can occur through misclassification of the exposure as well as through misclassification of the health effects.

Information bias through misclassification of personal exposure — for example to air pollution — can occur if the exposure in the living environment is different from that in the occupational environment . Misclassification can also occur if the exposure occurred many years before the health effect ('time lag'), which makes it difficult to measure the exposure in question. However, selection bias can also occur in this situation, if, owing to migration, the current population is no longer the same as the population exposed in the past. If the misclassification of the exposure occurs proportionally in the study and the control population, the result is generally an underestimation of the risk (Arm98). However, particularly when group average exposures are used ('Berkson type error'), greater caution is necessary in the interpretation of misclassification of exposure.

Information bias through misclassification of health effects may, for example, occur owing to differences in reporting, diagnostics, registration, coding, the admission and treatment policy, or the availability and accessibility of health care. An example of this is the reported increase in cancer cases in surrounding residents some years after the incident with the Three Mile Island nuclear power plant near Harrisburg (Hav99). As this increase could not be explained by the small amount of radioactivity emitted, they assumed that changes in help-request behaviour and, also because of this, in diagnostic activities were responsible for the increase. This assumption is strengthened by the fact that there was a decline after the initial increase. Over-reporting — conscious or otherwise — of non-specific health complaints may also be seen as information bias (Lee92).

Confounding

Health status depends on countless factors, including age, gender, level of urbanisation, socio-economic status, ethnicity, smoking habits and other lifestyle factors. The health services can also affect the health status. The effect of these factors may differ considerably, with all the consequences for confounding the study of the relationship between local environmental exposure and disease.

A confounding factor (confounder) is described as a known risk factor that is associated with the exposure being studied but which is not an intermediary factor in the

causal relationship between exposure and effect (Rot98). The question therefore arises as to whether concerns about environmental risks can be seen as a possible confounder in the relationship between exposure and effect (Neu91).

Given the availability of sufficient data on relevant risk factors, it is possible to adjust for confounding. At the neighbourhood level, particularly characteristics such as the socio-economic status of the surrounding residents of a source of pollution can result in an apparent link between exposure and health effects (Ell95a). Therefore, it is essential to adjust for socio-economic status, if not at the individual level then at the aggregated level. Some researchers consider aggregated measures of socio-economic status, such as average income, to be an even better predictor of health status in a neighbourhood than individual indicators, such as education and employment (Big99). Others find no difference between individual and aggregated measures for socio-economic status and effects on health (Hof98).

Each descriptive or 'ecological' study of the occurrence of disorders in highly exposed areas or populations, in which adjustments for confounding are not usually possible at the individual level, is confronted with the problem that not all people in that population necessarily face an increased health risk. Incorrectly translating associations at the population level to the individual level is known as the 'ecological fallacy' (Mac00). An example of this would be the lack of an association at the population level between the radon concentration in homes and the occurrence of lung cancer, if most of the people living in the homes with high radon concentrations were non-smokers (Gre94).

All these epidemiological explanations for local variations in health problems can make it difficult to unambiguously interpret the results of descriptive epidemiological studies using data already available, especially in the context of a local environmental problem.

5.3.2 *Useful indicators and databases*

For the feasibility of an epidemiological study based on data already available, the Committee refers to some compilations of the National Institute of Public Health and the Environment (RIVM) containing possibly useful health indicators in databases in the Netherlands for local monitoring activities (RIVM93, RIVM97).

When choosing health indicators, the most important criteria are: low aggregation level, completeness of the data in the region, the relevance to the exposure in question, and the reliability of the records. The most suitable records on the basis of this are those of pharmacies, hospital discharge diagnoses of the National Medical Register (LMR), the National Obstetrics Register (LVR) and the National Cancer Register (IKC). The

following databases are useful in the case of specific disorders, that of the Netherlands childhood leukaemia working group foundation (SNWLK), and the European Registration of Congenital Anomalies (EUROCAT). The usefulness of the various registration systems of general practitioners needs to be examined in greater detail.

Other examples of useful population data and data on other possibly confounding factors at a low aggregation level are: age composition and socio-economic neighbourhood characteristics, such as the unemployment percentage, population density, average income, percentage owner-occupied homes or average number of years of education (in the 'Social Environment and Lifestyle' database of the Statistics Netherlands (CBS)). More commercial organisations can also supply similar data.

The Ministry of Housing, Spatial Planning and the Environment, the CBS and the National Institute of Public Health and the Environment (RIVM) have location-based environmental indicators from supraregional registers, including data on emissions into the air and surface water, soil use, traffic intensity, drinking water quality and housing stock.

In England, as a result of the leukaemia cluster in Sellafield, various national registers were combined in the Small Area Health Statistics Unit (SAHSU) in London (Ell99). This covers: births, stillbirths, other deaths, hospital admissions, cancer incidence, prevalence of congenital abnormalities, population data (such as socio-economic status), and environmental data. The objectives are:

- investigation of unusual disease clusters
- study of health statistics in relation to suspected point sources
- study of geographic variation in the occurrence of particular disorders
- development of methods for cluster detection
- development of methods for descriptive or ecological studies ('small area health statistics').

This London-based institute has published many articles on subjects that gave rise to a great deal of public concern, including an investigation into the health risks posed by blast-furnaces, waste incineration plants, waste dumps, radio and television transmitters and busy roads (Ell96*)*. The national character of the descriptive epidemiological studies means that the results are more reliable than those of studies that focus on a single local cluster. A limitation of the SAHSU studies is their limited exposure characterisation.

5.4 Review

Stepwise approach to cluster reports

The Committee believes that the report of a disease cluster is sufficient cause for action. It endorses the stepwise approach to disease clusters that is used by municipal health services. This enables a quick and adequate response to cluster reports. On the basis of an initial pragmatic approach (orientation and verification phase) an examination is conducted to determine the extent to which a quantitative cluster investigation or a quantitative exposure assessment is advisable. This approach has to be combined with a process of risk communication in accordance with guidelines summarised in 3.5.

Quantitative cluster investigation: descriptive epidemiological studies

In practice, quantitative confirmation of a cluster report often proves to be unnecessary. If it is necessary, it is preferable, for demonstrating spatial differences at the municipal or regional level, to calculate standardised morbidity ratios (SMRs). SMRs are conceptually clear and therefore simple to interpret, provided the research and control populations are properly defined on the basis of the exposure; after all, boundary definition on the basis of the observed health events could cause selection bias. The Committee stresses that an increased risk of disease at the aggregated or group level (neighbourhood, region) need not be an indication of a causal relationship to the supposed local environmental factor, as possible confounders are not always paid sufficient attention.

When spatial differences in SMRs are determined at the postcode level, it should be taken into account that they may largely be based on coincidental fluctuation, for which corrections must be made, using Bayesian smoothing, for example. The Committee believes that it is so complicated to determine and interpret SMRs at the postcode level and to use other advanced statistical methods of cluster investigation that these techniques should only be used by experienced methodologists who are also familiar with the limitations. Further development, validation and application of these cluster analysis methods could be useful for national research into — the causes of — clustering of relatively infrequent disorders, such as leukaemia, lymphomas and congenital abnormalities. Sometimes, studies of this kind can be initiated on the basis of a confirmed cluster. The Committee believes this is generally more useful than setting up a local epidemiological study of the effect of environmental factors that also occur elsewhere. This applies all the more so as, for some local exposure situations (such as traffic or electrical high-tension lines), hardly any health risk can be demonstrated, whereas, from the national point of view, the number of health events may not be negligible.

The Committee believes it is important for supraregional research into clustering of health events to be conducted by centres with expertise in the field of spatial statistics and cluster analysis. Moreover, they should have access to expertise on the disorder concerned, exposure modelling and environmental epidemiology. The Committee does not believe it is necessary to set up a specific centre for cluster analysis like the one in England, as long as the various data registries are able to work together properly. If necessary, the Health Care Inspectorate can play an intermediary role, if privacy aspects impede rapid access to health data. Also taking into account the limited number of cluster reports that would qualify for further cluster analysis (in the Netherlands an average of one cluster report is epidemiologically confirmed per year), a point for attention is the composition and maintenance of expertise and a technical infrastructure.

Further etiological epidemiological study

If more health problems are demonstrated at the group level, a further etiological epidemiological study of the local population may be considered, in which exposure and health data are collected at the individual level (Chapter 6). However, in that case, it is important to make clear to those involved that a causal relationship between local environmental factors and possible effects on health at the local level is hardly ever demonstrable, especially because of the relatively low number of health events. From the point of view of environmental management, it is often more effective to take measures on the basis of an exposure assessment and the associated health risks.

Chapter 6

Further epidemiological study

If both the number of health events observed by the local population and the suspected environmental exposure are high and a possible causal relationship is biologically plausible, the possible relationship between the local environmental exposure and the health problems can be further investigated in an etiological epidemiological study ('relationship track' cluster investigation). Health data and exposure data are collected at the individual level to enable this. In the Netherlands, no studies of this kind were conducted among the local population in the period 1993 - 1997 for any of the cluster reports that were submitted (RIVM99b).

Sometimes, studies among the local population are referred to as population surveys. Because this term (in Dutch) is also used for other types of studies, the Committee discusses the various opinions on population surveys in 6.1. In this advisory report, the Committee prefers to use the term further or etiological epidemiological study. In 6.2 the Committee discusses the limitations of epidemiological studies among the local population and in 6.3 it discusses the criteria that have to be fulfilled to make studies of this kind worthwhile.

6.1 Types of population surveys

Various types of population surveys are distinguishable according to the purpose of the study (Zie82):

- a study that focuses on the individual: offered to trace a disease, 'mass screening' for breast cancer, for example

- a study that focuses on a causal factor: scientific research into the effect of particulate matter or ozone on bronchial complaints, for example
- a study that focuses on the situation: to demonstrate or exclude damage to health caused by local environmental pollution, for example.

This advisory report is mainly concerned with the last type mentioned here, studies that focus on the local environmental situation. There are two approaches to this and combinations of the two are also possible:

- studies intended to ascertain whether there is a causal relationship between exposure to local pollution and health effects
- studies intended to provide help to the affected population by providing individual relief; studies of this kind mainly depend on the population's health care requirements.

Etiological epidemiological study

In the case of etiological or analytical epidemiological studies, a health survey (questionnaire) is offered to a group of people, in combination with a determination of their individual exposure, possibly by investigating the body burden, with a view to studying a causal relationship between exposure and health. In principle, studies of this kind, in which participants are actively approached, come within the scope of the Act on Medical Research Involving Human Subjects (VWS00). If the participants are also informed of the individual study results appertaining to them personally, it may also come within the scope of the Act on Population Screening (GR99b). See also annex C.

Auxiliary or individual medical examination

Auxiliary examinations focus primarily on the individual concerns and needs of the people involved. They are therefore not generally epidemiological in nature and provide little information about environmental causes of health problems. Studies of this kind do not therefore come within the scope of the Act on Medical Research Involving Human Subjects, but may come within the scope of the Act on Population Screening, namely if they are offered and conducted in order to trace particular disorders or risk indicators.

When the studies are conducted according to a particular system (all participants complete a list of complaints, for example), registering complaints and symptoms may also serve an inventory purpose. This can be combined with providing individual information, matched to the questions and complaints of those concerned. Careful checking with and, if necessary, referral to the local health services is essential. This type of medical relief and care provision is only occasionally appropriate for local environmental

problems but it may be valuable in major calamities, disasters or military operations that are combined with traumatic experiences that could lead to post-traumatic stress disorders. Relief of this kind was provided in the Netherlands after the air crash at Bijlmermeer, and the firework disaster at Enschede. It is usually not called for in more 'everyday' environmental situations and is therefore not considered further in this advisory report.

6.2 Methodological limitations of population surveys

Etiological epidemiological studies in the case of local environmental problems are confronted with various methodological problems (Wij90):

- a particular characteristic of non-specific complaints or disorders is that they may be caused at the individual level by numerous factors
- owing to the emotional situation and mutual contacts, many of those involved in the study will overestimate the nature and number of health problems they suffer
- health problem reporting can easily be biased by, on the one hand, selective attention to particular complaints and, on the other hand, selective participation in the study (selection bias)
- the exposed population is often not large enough to enable statistically reliable statements to be made about a link between the exposure and the complaints or disorders
- it is often difficult to find a suitable control population that, excluding the exposure, is comparable in all other respects (age, gender, lifestyle, socio-economic status, and so forth) with the exposed population
- some disorders have such a long latency period that they cannot be related to the exposure details within the period of the study.

6.3 Conditions for etiological epidemiological study

Etiological epidemiological studies in connection with local environmental problems should generally only be considered when both more health problems occur than expected and also a proper exposure assessment has shown the likelihood of the exposure being or having been high enough to enable health effects in the exposed section of the local population to be demonstrated.

To be able to demonstrate a relationship between exposure and effect, there has to be a contrast in exposure between the study population and a control population. As far as possible, with the exception of the exposure or the effect of the study, the control population should be comparable with the study population. Reference data gathered at the national level are therefore often less suitable as reference data for a local study popula-

tion. The Committee refers to 4.2.2 with regard to the decision concerning when individual exposure should be assessed internally (as body burden).

Regardless of a demonstrable increase in exposure, numerous aspects may play a role in any decision to start an etiological epidemiological study (ATSDR96, RIVM95, Rot90, Neu90):

- public health importance:
  - degree of over-incidence or prevalence
  - seriousness of the effects
  - size and sensitivity of the exposed population
  - prevention possibilities: measures, regulations and rules of conduct
  - importance for comparable situations
- involvement of local population:
  - possibility of involving key people in the population
  - concerns among the population
  - support for the investigation: more pros than cons
- scientific importance:
  - gaps in knowledge about exposure or effect
  - availability of methods for testing new hypotheses
  - possibility of making generalisations according to (importance to) other populations
- likelihood of unambiguous results (statistical power)
  - clear presentation of issues, thereby enabling local questions to be answered
  - making exposure, effect and confounding factors properly operational
  - sufficient variation in exposure
  - possibility of studying exposure-effect relationships
  - availability of reliable data on other risk factors, such as age-related habits and psychosocial factors
  - minimum bias and confounding
  - sufficiently large study population and adequate control population(s)
  - sufficiently high response expected in study and control group.

Other, more pragmatic, preconditions for studies of this kind are: sufficiently qualified staff, as well as time, funding and resources to collect the data, report and communicate about it.

6.4 Discussion

If the local population or politicians request a population survey, it is important to communicate at an early stage with resident representatives, politicians and professional

authorities about the expectations, possibilities and limitations of etiological studies using individually collected data. There is usually considerable pressure to conduct a further epidemiological study among the local population, yet, depending on the circumstances, the study's practical value in relation to local environmental problems will be fairly limited. This type of study generally involves major limitations, because of, for example, the lack of a sufficiently large study population, exposure that is difficult to objectify and the many possibilities for bias occurring in the results. This means that many people will be disappointed about the conclusions of the study.

The Committee believes that further etiological epidemiological studies in the case of local environmental problems should only be considered if, on the one hand, there has been an obvious increase in the number of health problems and, on the other hand, the exposure assessment indicates the need for such a study: i.e. if the exposure exceeds values at which effects on health can be expected. The study must also fulfil various conditions if it is to provide adequate information on the direct effect of environmental factors on health and thereby contribute to the required knowledge (see 6.3).

In the case of a local cluster of relatively unusual disorders, such as certain types of cancer or congenital abnormalities, a further epidemiological study (in this situation a case control study) in the local population will only occasionally provide the required information, as there are generally not enough patients. Likewise in the case of a cluster of non-specific health complaints, the Committee believes that, also because of the possibilities for bias, it will only occasionally be possible to use a further epidemiological study (in this situation a cross-section study) to demonstrate the plausibility or otherwise of a causal relationship to the suspected exposure. However, this could demonstrate the effect of other non-physical environmental factors on the health problems experienced, including factors such as concerns about exposure.

If it is demonstrated that exposure is so low that it is unlikely to affect health, the Committee believes an etiological epidemiological study will not generally have any added value. However, if the local population remains unconvinced that no effects on health can be demonstrated, social concerns may occasionally form an additional reason for considering conducting a further study. The specification of the aim of any such study and communication about its possibilities and limitations are extremely important and should be in line with the specific situation. It should also be made clear that the establishment of a causal relationship between the suspected exposure and the health problems is not expected. When considering conducting studies of this kind, it is important to consider not only the intended benefits (possible reassurance, if no effect is demonstrated) but also the disadvantages for the participants in the study (emotional burden, false sense of security), certainly if the study is combined with blood or urine analyses.

In conclusion, the Committee believes it is necessary to give critical consideration to any decision about whether or not to conduct an etiological epidemiological study among the population concerned.

Chapter 7

Practical guidelines

The practical guidelines presented in this chapter on risk communication, exposure assessment and cluster investigation are mainly intended for local government, and especially the municipal health service. Other (local) governmental authorities and professional groups are advised to deal with any reports on health problems that those involved relate to local environmental pollution in consultation with the municipal health service.

In drafting these guidelines also several recently compiled Dutch guidelines were uesed, developed for specific problem situations, such as soil pollution, air pollution by industry or multi-burners, cancer clusters, and so forth. The Committee points out that hardly any research has been done into the practical value of the guidelines. Its proposals are therefore mainly along the lines of good public health practice, which, taking into account the interests of those involved, can be used to respond effectively to local environmental problems.

Take concerns about exposure to local environmental factors seriously

The main recommendation is that concerns about health complaints or disorders in relation to local environmental factors should be taken seriously, by examining how those involved experience the problems and by promptly taking proper action. Moreover, a lot of attention should be paid to the risk perception of those involved, as it is generally determined by their lack of familiarity with the risk, by the fact that they feel they have no control over the situation, or because of a lack of trust in the information source. The

main factors that determine trust in the authorities concerned are expertise, openness and empathy. This means that local government and municipal health service workers must be able to develop adequate skills in this field.

Pay prompt attention to risk communication and public participation

Proper risk communication consists of an exchange of information and opinions between all the parties involved about the nature and size of a risk. It is also necessary to take into account possible differences in opinion between specialists, on the one hand, who tend to emphasise the quantitative aspects of the risk and, on the other, citizens, whose opinion, given their immediate involvement, depends much more on qualitative aspects, such as the nature of the exposure (involuntary, unknown, uncontrollable), uncertainties about possible health risks and the credibility of the information source.

Sometimes, it is possible to provide clarity by comparing an environmental risk with other more familiar but in other aspects similar risks. However, it is important not to trivialise the risk that concerns the population. The main aim is to show the risk in a realistic perspective. The Committee stresses that comparing environmental risks with dissimilar risks, such as accidents may have the reverse effect from that intended.

The Committee believes residents should be involved in the approach to local environmental problems, especially in discussions about the possibilities and limitations of investigations into the suspected exposure or health problems. Public participation of this kind can lead to greater mutual understanding and also help residents regain the mastery on the situation they believe threatens them and their trust in the authorities concerned.

The Committee believes that risk communication between government, the population and interest groups should not only be an issue after an insight has been obtained into the exposure and possible health risks. It is precisely in the initial phases of reporting and dealing with a local environmental problem that it is important to obtain a proper impression of the concerns that have arisen about the possible link between local environmental factors and health.

Make a systematic and transparent exposure assessment

The Committee believes risk assessment is the appropriate instrument for assessing the health risks of suspected local environmental exposure and for evaluating the possible environmental cause of disease clusters. To this end, the estimated exposure is compared with health-based recommended exposure limits and known exposure-effect relationships. The definition of the problem and results of this risk assessment process should come about through the participation of all those involved and feedback to them.

In the case of local environmental problems, it is generally sufficient to assess external exposure. However, it is also necessary to take into account background exposure and exposure to other sources and agents that have a similar effect. Given the technical and ethical problems associated with the interpretation of the measurement results, the Committee considers it only appropriate to assess internal exposure (body burden) if various conditions have been fulfilled (see Chapter 4). Therefore, the Committee recommends that any such studies should only be considered if there is considerable uncertainty, and always in consultation with specialists in this field.

Consider taking measures in the event of nuisance or undesired exposure

As well as possibly preventing effects on health, measures taken at the source of pollution or rules of conduct to limit the undesired exposure or nuisance can also empower the local population to gain mastery on the situation and can restore trust in the authorities concerned.

Pay attention to possible physical consequences of stress

The Committee calls for those involved and policymakers to be informed about the phenomenon that chronic stress caused by concerns about local environmental pollution can unintentionally or unconsciously lead to non-specific physical complaints. Careful communication about this psychosomatic mechanism requires expertise. Therefore, health service workers, including municipal health service employees, should have sufficient insight and, if necessary, be given additional training about the way in which people may respond in uncertain and stressful situations. Knowledge about matters such as stress, symptom perception and attribution, which may be at the root of reported health complaints, is necessary for the interpretation or (arranging for the) treatment of complaints and symptoms.

Take a stepwise approach to environment-related disease clusters

When suspected disease clusters are reported that those involved relate to the environment, the Committee believes that both a systematic assessment of the exposure (‘environmental track’) as well as a study of the occurrence of health events (‘health track’) are necessary.

Take into account coincidence as an explanation of disease clusters

If members of the public have a good idea of what the average rate of occurrence is of a given disorder, unfavourable coincidental exceptions are more likely to be reported. The danger is that it will be incorrectly concluded from a statistical test that the confirmation of a cluster proves that something unusual is occurring. Disregarding coincidence, general risk factors relating to age composition or lifestyle in the neighbourhood may also result in more local health problems. It may provide clarity to explain that confirmation of noticeably many cases of a disease in a neighbourhood does not automatically mean that they are caused by a local environmental factor.

Be critical when conducting descriptive epidemiological studies

Following the verification phase, it can often be shown that it is unlikely that a disease cluster exists or that there is another explanation for the alleged cluster than the suspected environmental exposure. In the other cases, a study should be conducted using existing health records to determine whether there has indeed been an increase in the number of health events. To this end, the Committee believes that, in most cases, calculating age-corrected disease figures (SMR) for the area concerned will suffice. In the Committee's view, the most advanced geographical and cluster analysis methods are currently only suitable for studying the clustering of disorders and health complaints at the supraregional scale.

Explain when a further epidemiological study is advisable

The Committee thinks it is only advisable to conduct an etiological epidemiological study among the local population, with health and exposure data collected at the individual level, if the following conditions are met:

- it has been demonstrated that there are more health problems than expected
- the exposure is sufficiently high to enable effects on health to be demonstrated
- the exposure can be properly quantified
- there is a good chance of achieving unambiguous results: in particular, this means the study must be set up properly and there must be a sufficiently large study population.

If the above conditions are not met, the study will usually not produce any useful results that can help answer the questions that have arisen locally. This means there will be little empowerment for the policy; the population will be disappointed and there will conse-

quently be more reason for problems and stress. Other considerations that may play a role in a decision to conduct a further study are:

- concerns and the involvement of the local population
- public health importance
- scientific importance
- manpower and resources.

Involve risk communication specialists in the epidemiological study

In the event of a decision to conduct an epidemiological study among the local population, the Committee recommends that when designing the study attention should be paid to psychosocial risk factors such as risk perception, risk behaviour, concerns and the associated level of trust in the authorities. In that case, it is also advisable to involve risk-communication specialists in the study design. They can advise on the presentation of the study results.

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A Assignment

B The Committee

C Terminology

D Prevalence of non-specific health complaints (VOEG)

Annexes

Annex A

Assignment

The Health Council's Work Programme of Activities for 2000 contained the following text:

Local relationships between the environment and health (439)

Suspicions sometimes arise that various people in a specific place contract a particular disease within a short period and that an environmental factor may be to blame. Disease clusters of this kind often lead to concerns among the local population. The Health Council of the Netherlands will examine the degree to which epidemiological studies could help provide clarification about the causes and thereby prevent both unnecessary concerns and misplaced reassurances. The future advisory report will also examine issues concerned with risk perception and risk communication.

Annex **B**

The Committee

- RM Meertens, *chair*
  psychologist; University of Maastricht
- C van den Bogaard, *advisor*
  medical-environmental inspector; Environment Inspectorate - Central Office, The Hague
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  epidemiologist; TNO Prevention & Health, Leiden
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- JJL Pieters, *advisor*
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- MM Verberk
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Annex **C**

Terminology

Analytical or etiological epidemiological study:

Study in which the exposure and health or disease are determined on the basis of personal data, with the intention of ascertaining the relationship between exposure and health.

Descriptive epidemiological study:

Study in which the exposure and health or disease are determined on the basis of data already available at the aggregated (group) level, sometimes referred to as an 'ecological' study.

Population screening:

Medical examination of people, which is conducted in connection with implementing an offer made to the entire population or a population category, with the aim of tracing, also for the benefit of the people being screened, diseases of a particular nature or particular risk indicators (VWS96). The primary objective is early diagnosis. Participants are informed of the study results that concern them personally.

Cluster:

A unusually high number of similar disorders or health complaints in a defined area, period or population.

Auxiliary or individual medical examination:

Study that primarily focuses on the individual concerns and needs of the people involved.

Local environmental problem:

In this advisory report, a situation in the local physical environment that various people experience as negative.

Environmental calamity or disaster:

An event (concerning hazardous physical or chemical agents) that poses a serious threat to the life and health of many people or major material interests (Sta95). A disaster differs from a calamity by being greater in total size and more serious (Vel98).

Monitoring:

Systematic, sequential examination of a characteristic that may change over time; in this advisory report, especially characteristics of exposure or health.

Risk:

Likelihood that in a particular situation a particular degree of damage will occur to the health of humans, the environment or goods.

Risk management:

Measures and rules of conduct intended to reduce a risk.

Risk perception:

The risk assumed to exist by a person involved; this is sometimes referred to as the opinion about the risk or the experience of the risk.

Risk assessment:

The process of exposure and risk characterisation.

Risk communication:

Exchange of information and opinions between the parties involved about the nature and extent of a risk or other factors that lead to concern, opinions or reactions about messages communicating risks (NRC89).

Annex **D**

Prevalence of non-specific health complaints (VOEG)*

See table on the next page.

* VOEG: (Vragenlijst voor Onderzoek van de Ervaren Gezondheid: a questionnaire for investigating the level of perceived health). The VOEG score of the general Dutch population is relatively stable over time. For this reason too, it is advised to compare current VOEG complaints of a local population with the (separate) VOEG complaints, as reported in the Health Questionnaire of Statistics Netherlands (CBS), provided factors such as age, gender and socio-economic status are taken into account.

Occurrence of 23 VOEG complaints, Health Survey 1998, total population of 16 years and older (group size: 7,429).

	VOEG description	percentage of persons with complaints
-	regular coughing complaints	15
-	pain in chest or heart region	7
-	palpitations	15
-	frequent pain in gastric region	8
-	stomach frequently out of order	15
-	often sneezing fits	17
-	regularly stuffed nose	21
-	frequently short of breath	9
-	troubles with pricking feeling in nose	14
-	troubles with insomnia	15
-	pain complaints in bones and muscles	27
-	back troubles	34
-	frequent fatigue	31
-	frequent headache	26
-	frequent vague stomach complaints	15
-	frequently dizzy	10
-	numb feeling or tingling	21
-	frequently aroused	13
-	frequently listless	18
-	rheumatism	4
-	frequently nervous	17
-	tired sooner than usual	23
-	quickly irritated	17

Annex **E**

Prevalence of protracted disorders

See table on the next page.

Protracted disorders in 1997/1998 (in %).

	male	female	0-14	15-24	25-44	45-64	> 65
asthma, chronic bronchitis or COPD	8.1	8.4	10.3	7.7	6.4	7.5	12
nasal sinisitis, sinusitis or maxillary sinusitis	7.2	10.6	6	8.6	11.6	9.5	6.2
serious heart condition or myocardial infarction	2.6	1.7	0.2	0.1	0.4	3.2	10.8
hypertension	6.4	8.8	0	0.8	3.6	13.6	27.9
(consequences of) stroke	0.6	0.4	0	0	0.2	0.8	2.4
gastric or duodenal ulcer	1.2	1	0.1	0.6	0.9	1.8	2.9
serious intestinal disorders, over 3 months	1.6	2.3	1.4	1.5	1.3	2.4	4.4
gall stones or gall bladder inflammation	0.3	0.9	0	0.3	0.5	1	1.8
liver disease or liver cirrhosis	0.3	0.3	0	0.2	0.3	0.5	0.3
kidney stones	0.6	0.5	0	0.2	0.5	1.3	0.7
serious kidney disease	0.2	0.2	0.2	0.1	0.1	0.4	0.6
chronic bladder inflammation	0.3	1.9	0.3	1.2	1	1.2	2.8
prolapse		2.3	0	0.1	1.2	4.3	7.8
diabetes mellitus	1.9	2.1	0.3	0.2	0.6	3.5	8.2
thyroid gland disorder	0.5	2.2	0	0.5	1	2.1	4.6
back complaints of persistent nature, longer than 3 months, or hernia	7	8.9	0.4	3.9	7.9	14.2	14.2
arthrosis of knees, hips or hands	4.7	9.6	0.1	1.2	2.7	12.7	28.1
arthritis (chronic rheumatics, rheumatoid arthritis) of hands or feet	1.7	3.1	0.2	0.6	1.4	4.4	7.6
other chronic rheumatism, over 3 months	0.6	1.5	0	0.2	0.7	2	3
epilepsy	0.6	0.4	0.4	0.2	0.5	0.6	0.6
dizziness with collapse	1	2.1	0.5	2.8	1.1	1.4	3.8
migraine	3.5	8.8	1.7	6.3	8.4	8.5	4.2
serious skin disease	1.5	1.6	1.4	1	1.3	1.5	2.7
malignant disorder or cancer	0.9	0.9	0.1	0.1	0.4	1.5	3.7
number of abovementioned protracted disorders per person							
none	65.3	55.6	80.2	71.5	63.4	47.2	31.1
1	23.6	25.1	16.5	21.8	25.3	28.9	29.7
2	7.4	11.3	2.9	5.1	8.1	13.4	20.4
3	2.4	4.6	0.3	1.3	2	6.5	9.2
4 or more	1.4	3.5	0.1	0.3	1.1	4	9.6
Sample size	8.329	8.566	3.669	1.919	5.319	4.003	1.982

CBS publication: Handbook health statistics 2000.