CHAPTER NINE

Investigating health issues

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Learning objectives

By the time you have worked through this chapter, you will be able to:

- **Read scientific reports and understand basic biomedical concepts and processes (such as drug testing);**
- **Look for reliable sources on health issues;**
- **Understand and explain changes over time in medical information;**
- **Examine key conditions (HIV/Aids, TB, malaria, diabetes, diseases of poverty) in light of some basic issues;**
- **Summarise often complex health care issues for your audience ;**
- **Compare the different views that people can have on health, illness and medicine;**
- **Think about the many ways that health issues can affect communities.**

This chapter assumes that you have some understanding of basic investigative journalism techniques. To learn more about, or refresh these, see Chapters 1-8 of the handbook.

Konrad Adenauer Stiftung

Finding your story

When we consider the health and science stories our newspapers or magazines carry, we tend to think either of routine self-help columns ("How to avoid heart disease") or of sensational – even scare – stories about 'killer' diseases and 'miracle' cures. The former are barely interesting to investigative reporters; the latter are too often shallowly reported as hard news and then forgotten.

But the area of health and science is sorely in need of investigative reporting. And often the biggest health stories come from issues that are accepted as a normal part of life, or are not considered important enough to worry people with the power to make a difference. Some examples of this are: the effects of chronic malaria; health conditions resulting from poverty, like diarrhoea; and the high incidence of cancer amongst people living near waste dumps.

FAIR's transnational health investigation

The Forum for African Investigative Reporters (FAIR) conducted its first transnational investigation on a health theme: why it was so difficult and expensive to access badly needed drugs in many African countries. This was something that people in many countries had been complaining about for many years: it had become 'part of the landscape'. But its impact was devastating. People with life-threatening conditions – including some FAIR members – were dying because they could not access the drugs they needed. You can read the investigation at http://www.fairreporters.org/portal/pdf/FAIR_proof_4.pdf and read more about how the investigation was carried out in Chapter 3 of the handbook.

Many of our stories about health rely on published research. In Chapter 2 of the handbook, Joyce Mulama describes how her story on an abortion pill was sparked simply by reading such a report. So sometimes there is a story waiting to be told in a study that could affect many people, such as the studies on the possible link between hormonal contraception (the pill) and ovarian cancer. Here, our role is to make that research accessible to our audience, and explain its impact.

But we have a bigger role too. National health agencies will, if they can, offer funding for studies on issues that interest government – but researchers can also begin looking at health issues or the need for new treatments because media attention has created a stir. There had been no new research into medications for tuberculosis for about 40 years – until the media in the West picked up on the increasing number of hard-to-treat tuberculosis cases in Europe and the USA. Journalists can actually be a catalyst, bringing to official and scientific attention an area where research is needed. Talking to practitioners and clinic staff, and asking community members about health issues should be a part of filling your investigative ideas book.

This, however, is only the start. Such initiatives can fall flat – or, worse, misinform or cause panics – if as journalists we do not deepen our knowledge of how science, medicine and research work, and of the context within which they operate. So this chapter begins with some basic definitions and discussions about health and science.

READ & respond — Some basic definitions

Before you go on, think about the definitions you currently use. What do you mean when you use the following terms? Note your ideas here.

- **Health?**
- **Medicine?**
- **Science?**

Investigating health issues: health is about people

The word health has many meanings, which can change depending on time and context. A basic meaning is "not being ill". However, different people and societies can interpret this in alternative ways. For example, "not being ill" might mean "physically able to perform work". Under this definition, a person living with an HIV infection who is not at the stage of Aids is considered healthy. But "not ill" could also mean "does not have any future constraints on her/his ability to work". Applying this definition to the same person would mean that person **is** considered ill – because the person is living with the possibility of future illness.

Concepts of health depend on how well a medical condition is understood, a person's age, gender and class, and the expectations about a person's economic and social roles. The notion of 'health' is a way of thinking about a person and that person's place in society.

'Modern' medicine

When governments and NGOs talk of hospitals, clinics and healthcare workers, they are referring to a particular system of thinking (ideology) about health. This system is based **on** the principles of scientific observation and is based **in** the material world: health and illness are contained within each person's physical body, or individual biological systems. This ideology is called biomedicine (allopathic medicine).

Biomedicine is sometimes called "modern scientific medicine". It developed with the growth of science and technology in Europe and North America during the 19th and 20th centuries. Biomedicine focuses on treating an individual's physical problems and does not try to address how a person relates to his or her social, political and economic surroundings.

Western European colonisers brought their biomedical health care systems to the countries they colonised. Sometimes they used the successes of biomedicine in treating physical ailments to help justify the colonisation of a country. The laws of many colonies were written to reflect the idea that biomedicine worked and local forms of healing did not. Most countries' laws still view allopathic therapies as the norm and local or traditional ideas about health (where they are granted any status at all) as 'alternative' or even witchcraft.

However, allopathic therapies are usually expensive to build, run and maintain. Few countries outside of Europe and North America (with the notable exception of Cuba) can easily afford to make biomedical coverage accessible for the majority of their populations.

Traditional ways of understanding health and medicine

The local forms of healing that European colonialists encountered in Africa are still often called "traditional medicine", to reflect the idea that they are based in social traditions separate from the 'modern' state. Another term is "indigenous medicine". The systems of understanding health and medicine called traditional medicine do not conform to biomedical concepts and are often specific to certain areas and societies.

Traditional medicine looks at a person's physical symptoms as reflective of what is going on in that person's life, including relationships to the community and the environment. (Contrast this with biomedicine's view that physical symptoms reflect what is going on *inside* that person.) This can mean looking at possible spiritual or community-based origins for an illness. The person is considered cured once the physical symptoms are gone.

Though biomedicine is usually given the most official backing, traditional medicine is actually the most widely used form of health intervention in most parts of the world.[1] Often traditional medicine is simply the only available form of health care. For example, in Ghana as of 2001 there were approximately 1 200 biomedical doctors and about 50 000 traditional healers.[2] The World Health Organisation estimates that about 80% of the population in sub-Saharan Africa uses traditional medical services before seeking allopathic care.[3] Where biomedical services are accessible, people frequently use both allopathic and traditional medicine at the same time.

Traditional medicine is often seen as less legitimate or useful than biomedical services. In part, this is because it is judged by biomedical standards. Traditional remedies also do not usually have the same physical effects as biomedical treatments and are often seen as less effective at treating an individual's physical body.

Judging what works

The legacy of colonial ideas and the formation of modern nation-states (or state-nations in the case of many former colonial countries[4]) continue to have important effects on ideas about health. The construction of global regulation bodies, like the World Health Organisation (WHO) and World Trade Organisation (WTO), has given biomedicine a global role as the standard for health issues. A health intervention or medicine must meet biomedical, scientific and ethical criteria.

Biomedicine does have a good success rate in curing people's physical ailments, but it is very limited by issues of access and accountability. Biomedicine's inability to see health problems in context also has important effects on whether a treatment *can* work.

A number of issues affect access to drugs

A woman living in rural Malawi was interviewed in June 2007. She had recently been diagnosed HIV positive and qualified for free antiretroviral medications handed out by the government. The researcher wanted to know why she had not yet gone to get the medicines. The woman replied that she was busy saving up money for the travel costs, and was sure she would be able to get her medications in January. (Patients can usually only collect one to three months' supply of antiretrovirals at a time.) The researcher recorded that the woman was very thin with deep coughs that would stop her speaking, and she struggled to stand up. The researcher thought the woman had late stage tuberculosis (TB).

Issues like access to food, travel money to get to a clinic, or community support are not usually considered aspects of health in the biomedical framework. The next section will give you the tools to understand biomedical concepts and research, but it is important to keep in mind that health is about more than individual bodies.

Investigating health issues: understanding the science of health

Like any academic discipline, biomedicine has its own language. Doctors, nurses and researchers often use words and terms that both you and your readers may not understand or have even heard. This section will explain basic concepts in biomedical research. You can use this to decide if the information you are given is useful or even accurate and how to communicate it to your audience.

Health and the scientific method

When people say "the scientific method" they mean a particular way of collecting and analysing information. Western science is built on the idea that you collect material evidence on a problem using observation and experiments ('empirical evidence'). You must be able to measure the evidence you collect. This empirical evidence is then used to test your hypothesis (your guess, assumption or theory) about the causes or results of a problem.

Someone using the scientific method is supposed to be objective and consider all evidence, even if it does not give the expected answer. The evidence should be available to anyone else who wants to test it. A hypothesis is only valid until it is disproved. In other words, if someone else collects the same evidence in the same way and does **not** get the same result then the hypothesis is false.

This can get confusing because a hypothesis can never be absolutely proved to be true, just not proved false. The famous quote by Albert Einstein on this problem is: "No amount of experimentation can ever prove me right; a single experiment can prove me wrong." The classic work on this issue is Karl Popper's *The Logic of Scientific Discovery* (1934). For a discussion of how to use logic and proof when writing your stories, see Chapter 7 of the handbook.

'Best practice'

'Best practice' is a guideline on how to treat a health condition if all possible resources are available. It is based on all the evidence that scientists collect about that particular health issue.

Different standards

When treating uncomplicated *P. falciparum* malaria in the United Kingdom it is best practice to first give a combination of three medications. The patient is also automatically put in hospital for at least 24 hours.[5] But the World Health Organisation guidelines (developed for countries with fewer resources) only recommend a combination of two or more medications at the same time. Automatically putting the patient in hospital is not in the guidelines.[6]

One of the most confusing things about biomedicine is the way scientists can say what they claimed last year was 'best practice' is not recommended this year. This is because of the scientific method. If new evidence is collected about a health issue and a previous hypothesis is proven false, scientists will change their recommendations for treatment. That is why journalists doing web-based research need to check the date of any scientific articles, and cross-check old articles against more recent ones.

If you are dealing with information about a diagnostic test, try to discover what is considered the optimal test for that health condition. This is known as the Gold or Criterion Standard and exists for most health issues. The Criterion Standard can also change over time with new information. (For where to search for best practice evidence and criterion standards, see the databases listed in the reading – but if you are in touch with a medical expert, it may be simpler just to ask.)

Evidence-based medicine

In the last 20 years there has been more effort to make sure that medical decisions are based on best practice evidence. This movement is often called "evidence-based medicine". It uses observations about patients from doctors and information about large groups of people that has been gathered by researchers.[7] Gathering and analysing information from large groups of people is sometimes called "population-based studies" and is part of epidemiology (the study of what factors affect health conditions in groups of people).

Epidemiology has become more important in making medical decisions since the 1950s, when British epidemiologists showed that smoking cigarettes leads to a high risk of lung cancer. They used statistical analysis to prove the relationship between cigarettes and lung cancer. Statistics are an important part of epidemiology and of evidence-based medicine.

Important differences between journalism and science

- Journalists often use 'theory' to mean simply an idea. Scientists use 'theory' to mean something that can make testable predictions and can be observed and measured.
- Journalists require multiple sources – but we mean only three or four. Scientists require far larger numbers, in repeated studies.
- Journalists use 'error' to mean a mistake. But error is an essential part of experimentation and statistical surveying; much scientific reporting is about how big or small the error in an experiment is – and how significant it is for the results. Don't take comments on 'error' in scientific reports to mean that the research was wrong.
- Likewise, scientific work is far more comfortable with uncertainty than journalism, and less prepared to offer hard yes/no explanations – at least until a very large volume of results are in. Beware of interpreting answers like this:
  Journalist: "Is migration a cause of the spread of this disease?"
  Scientist: "Yes, it is one factor. But other important causes include poor nutrition, … etc."
  News story headline: "Migrants cause disease says scientist."
- Journalists work on short timeframes. Scientists study something over often quite long periods of time and, as we have seen, their views can change as the results of studies and experiments come in over that time.

Investigating health issues: what is a biomedical study?

Biomedicine needs accurate evidence to make decisions about health and treatments. Humans are complicated organisms; different people can react in diverse ways to the same stimulus. Sometimes the same medication will have a positive effect on a small group of people, but a very negative effect when it is tried by a much larger group of people. A person might react well to a medication the first week she tries it, but get very sick from the medication after a year of taking it. Biomedical research tries to gather as much evidence as possible about *if* a medication or treatment works, *how* it works, *when* it works, and for *how long* it works.

There are many ways to gather evidence on a health issue. In biomedicine there are clear guidelines about how to do this properly: you can also use these guidelines to judge if a study is acceptable.

Gathering information

Information can often be put into two categories. We can look for information on *what* people do, *when* they do it, and *how often* they do it. This is called quantitative information (because it looks at numbers or quantity).

We can also look for information on *why* people do something, and *how* they do it. This is called qualitative information (because it looks at value or quality).

Biomedicine tends to judge the value of a study by how it is done. Quantitative studies are often given more power than qualitative studies. This is because people can say one thing and do another, and it is easier to be sure that someone has done something when you have figures that say they did it a certain number of times. Qualitative studies take a lot longer than quantitative studies. It can be hard to collect enough data in a qualitative study to be confident that the collected information reflects the experiences of the larger group and not just the views of a few individuals.

Clinical trials

There are two general types of research into medications or treatments. **Observational studies** involve studying what usually happens to patients and measuring the effects or outcomes. **Interventional studies** involve giving the patient a different medication or treatment and measuring the outcome of that intervention.

In biomedical research there is a hierarchy of what are considered reliable ways to gather evidence from people on a health issue. At the top is a **randomised controlled trial** (an intervention study). Almost as good are **cohort** and **case-control studies** (both observational studies). At the bottom are **case studies**, **anecdotes** and **personal opinions** (sometimes called authority and bench studies).

When you read about research, it's therefore important to find out what kind of study was done. The results of a randomised controlled trial carry far more weight – and are therefore far more significant in news terms – than a small collection of bench studies.

Most clinical trials test a new medication or treatment against either a placebo (a look-alike with no medical effect) or the existing best practice for that health condition. Clinical trials can be at one health centre or across many health centres and many

countries. Most trials will have a protocol that describes how the trial will be done and patients in the trial will be treated. All trials should be approved by a regulatory authority and are often required by national authorities before the new medication or treatment can be used in a country.

The ethics and regulation of clinical trials

A clinical trial can be run by either the researcher doing the study or by the institution (the university, or government, or company) that funds the study. There is usually an ethics committee to approve every trial that involves an intervention. An ethics committee is also needed for any observational study that involves personal information about a patient. Every patient in a study, both intervention and observation, must give fully informed consent to participating in the study. A study is stopped if its ethics committee thinks that a patient's rights, safety or general well-being is threatened by participating in that study.

Full disclosure of information is an important part of making sure a clinical trial (especially an intervention) is ethical. A researcher cannot legally hide information about a medication or treatment that could put people in danger. But a researcher might interpret information on adverse events (or unexpected problems with a treatment) as not related to the actual intervention and then not tell anyone about the problem. The company or institution that sponsors a trial might also decide not to publicise potential issues. National regulatory agencies approve a treatment for general use on the basis of the information they receive, so false or misleading information is a huge problem.

Is all the information actually out there?

In 2008 an academic study discovered that most research saying antidepressants do not work does not get published. The researchers looked at 74 studies on 12 different antidepressants. 37 of the 38 studies that suggested the medications worked were published. But only three of the 36 studies that implied the drugs might not work were printed. Research that does get printed will sometimes change the results to suggest the medications work. 11 studies with negative results were re-written to suggest that the antidepressant had worked. – Gene Emery, Reuters.[8]

Companies or institutions often conduct clinical trials in countries that do not have regulatory authorities or where the regulatory authority cannot enforce standards. Over a third of clinical trials happen in countries with little official oversight.[9]

Be sure that when you read about trials, you distinguish between those where the medication was actually harmful or ineffective and those that were banned or stopped simply because they did not respect ethical requirements.

Exercise — Drug trials

Find out:

- What body controls drug trials in your country?
- What are its ethical requirements governing such trials?
- What are the name and contact details of the body's media spokesperson?

A randomised controlled trial (RCT)

Biomedicine often considers an RCT the most reliable kind of clinical trial. It measures how well a new medication or treatment works in controlled circumstances. Patients are randomly assigned to the **intervention** part of the study (where they receive the new medication or treatment) or the **control** part of the study (where they receive either a placebo or the current best known medication or treatment for that condition). This is important. Random assigning means that, statistically, any known and unknown factors that could affect the condition are just as likely to affect the intervention as the control part of the study.

RCTs are also divided into **open**, **blind** and **double-blind** studies. This affects how much both the patient and the researcher know about the medication or treatment. (Often a patient or researcher can imagine a particular outcome because they believe there should be that effect from the medication or treatment. Sometimes, patients may actually claim they feel better, because of this psychological impact. This is called the Placebo Effect.)

- An **open** RCT means that both the patient and the researcher know to which part of the study the patient is assigned – the intervention or the control part.
- A **blind** study means the research knows but the patient does *not* know whether or not the patient is in the intervention or the control part of the study.
- A **double-blind** study means both the researcher and the patient do not know what medication or treatment the patient is getting (i.e. if the patient is in the intervention or the control part of the study).

Some clinical trials cannot be blind or double-blind because of the nature of the treatment or medication. For example, if a clinical

trial wants to test how well a liquid form of a medication works in comparison to an existing pill form, it will be very easy for the patient and researcher to guess whether or not the patient is in the intervention or control arm of the study.

One of the biggest problems in an RCT is making sure that the patients in the intervention and the control parts of a study are similar in terms of age, sex and health status. This is called selection bias. If the parts are skewed (i.e. not equal) then it is very hard to tell if the medication or treatment was the cause of an outcome, or if the difference between the groups was the reason for that outcome. Study size and randomisation are important in addressing these concerns.

RCTs are usually expensive. RCTs also rely on statistics to interpret the data gathered during the study. Statistically there is a possibility with every study that the information will be wrong. Researchers do as much as possible to make that statistical possibility very small (i.e. 1% is usually acceptable), but if many studies are done on the same subject this means there will almost always be at least one study that says the opposite. For example, if 300 studies are done on the same issue and every study accepts a 1% chance of getting it wrong, then there is a statistical possibility that three studies will have a false result.

Phases of testing a new or different intervention

There are five parts to testing a new or different intervention (a medication or treatment). Each one of these five phases is often treated as a separate clinical trial. Usually the process takes years, and new or different medications will only get approved for use by national regulatory authorities after the first four of the phases are completed. On average, this will take eight years. The last phase looks at what happens when the new or different intervention is available to everyone after approval. The first phase is *in vitro* (in a laboratory) and sometimes *in vivo* (in a living organism) in animals. The next four phases are always done on human beings (*in vivo)*.

1 Pre-clinical studies

This involves looking at the effects of a new or different intervention in test tubes or in animals. The results of this phase are used to decide if the treatment might have an effect in humans, and if it is safe to test in humans.

2 Phase I

A Phase I trial is sometimes called a safety trial. In this phase a small group of healthy volunteers (i.e. people who do not have any health conditions) is usually selected. However, if there is a group of patients who already have the health condition for which the treatment is designed, and who do not have any other treatment options, then these patients can also be selected.

Researchers look for any problems caused by the new or different treatment. The amount of medication needed to create an effect, or dose range, is also measured. Sometimes the treatment being studied is combined with different medications to see if outcomes change.

3 Phase II

If an intervention passes its Phase I trial, then it goes into a Phase II trial. In a Phase II trial there are more people involved and researchers start to look at if the intervention actually works in the way it was designed to work. (Data on the safety of the treatment is still collected.) Most new or different medications fail in Phase II trials.

Sometimes a Phase II trial is divided into IIA and IIB. A Phase IIA trial looks at how much of a treatment (or dose) is needed to get an effect, while a Phase IIB trial looks at how well each level of dose works. A Phase II trial can be combined with a Phase I trial and can be a case study.

4 Phase III

Phase III trials only happen if a treatment passes Phase II (i.e. it is still safe and there is now an established dose for the medication being studied). This stage looks at what happens when the intervention is used in a larger population with many factors that can affect how well the intervention works. Phase III trials are always RCTs. This is the most expensive and longest part of approving a new or different health intervention.

Sometimes an intervention will get approved while the Phase III trial is still going. This allows patients who have no other treatment options to get the trial treatment before it is available for general use.

If the Phase III trial of an intervention shows it works, then all the information about it from every trial is put into a single document and given to national regulatory authorities like the USA's Food and Drug Administration (FDA).

5 Phase IV

This last trial sometimes does not happen. It takes place after an intervention is approved and distributed. Sometimes a national regulatory authority will require a Phase IV trial. This phase looks at the long-term effects of a new or different treatment, or what happens when it is given or taken by people who did not meet the criteria of Phases I, II or III.

Just because it's approved...

In 1999 the American FDA approved a new kind of painkiller, rofecoxib, which was marketed under the name Vioxx. It quickly became a common medicine for certain types of acute and chronic pain, like arthritis. A Phase IV study then discovered that heart attacks were much more likely in patients already at risk of heart conditions who took Vioxx (as opposed to other kinds of painkillers). In 2004 the company that produced Vioxx voluntarily withdrew it from the market.

A cohort study

A cohort study looks at what happens over time to a group of people who share a biological trait or a kind of experience (like doing the same work; being born in the same year; took the same medication). This group – the cohort – is compared to either a larger group of which the cohort is part, or to another cohort of people.

Cohort studies are observational studies. A researcher who wanted to know if working in a mine could lead to tuberculosis might track two groups of young men from the same village who finish grade 9 and go to work in either a mine or on a farm. The two groups of young men would start off with the same health, education and environment. If the incidence (or change over time) of tuberculosis in the cohort who went to the mines was higher than amongst the cohort who went to the farms, then the researcher would probably conclude that working in the mines was more likely to cause tuberculosis.

'Prospective cohort' studies decide on who is in the cohort before the study is started. 'Retrospective cohort' studies define the cohort after the study is done. Our theoretical example of the tuberculosis incidence among young men from the same village working either in the mines or on the farms is a prospective cohort. If we were to first look at the tuberculosis rate among young men from the same village and then divide them into those who worked on the farms and those who worked in the mines, then that would be a retrospective cohort.

A case-control study and a cross-sectional study

A case-control study compares two groups of patients: those who have a particular medical condition and those who do not have that condition. Researchers then look back in time to see what the two groups did the same or differently. This kind of study is easier than an RCT or cohort study as the patients are already identified and there is no intervention. The famous study in the 1950s that showed people who smoked were more likely than people who did not smoke to develop lung cancer was a case-control study. (The researchers looked at doctors who did have lung cancer and those who did not, then asked what the two groups did the same or did differently.) Often case-control studies are used to justify doing a RCT or cohort study.

Unfortunately, it is hard to use a case-control study to show that an outcome has a definite link to a problem. Most case-control studies will just suggest that an outcome might be linked to a particular issue. This is because the researcher cannot control the choices people make that might put them in the group that develops a specific condition or that can put them in the group that does not develop that condition. As a result some researchers say that case-control studies must always be treated with scepticism.

A case control study

A case-control study found women past menopause who received artificial hormones (HRT) were less likely to have heart disease than post-menopausal women who did not receive the medication. But further research showed that the hormones were not the reason for the decrease in heart disease (and in fact might *increase* the risk of heart disease).[10] The case-control study was confused by the fact that women who could afford artificial hormone therapy after menopause were usually richer than women who could not afford the therapy. Most of the richer women had better health, better diets and exercised more, which decreased their risk of heart disease.

A cross-sectional study is the same design as a case-control study, but it looks at the issue at a single point in time and not over a period of time. It is also called a prevalence study. This is often cheaper and easier to do than a case-control study, but it is hard to tell what factors are the cause or the result of a health condition.

A case study

A case study takes a detailed look at a single event or case. (Again, this is an observational study.) A case is usually chosen because it is rich in information about the issue a researcher wants to study. This means that typical or average events are not usually chosen, unless the researcher is trying to make a point about the average kind of case. The researcher will look for the hidden or deep causes of a problem and what consequences it might have. Case studies do not try to measure how common a problem is or just describe its symptoms.

Study size

The size of the group or groups in a study is very important in judging its value. If a study looks at a problem affecting a large group of people, then it will usually need to collect data or information from or on a bigger number of individuals within that group. (If the group is bigger than 20 000 then this does not apply in the same way.)

The amount of data that a study has to collect so that its information has value is determined by a mathematical formula. The formula helps researchers decide if – given important variables – they can be confident that their information reflects a hypothesis that best fits the group they are researching. (This is called the Confidence Interval and is written as CI. Most research tries to get a CI of 95% or higher. In other words, researchers aim to establish that they are over 95% confident that their gathered information reflects the reality of the group being studied.) However, if a health condition only affects a small number of people then it might not be possible to get enough patients so that the study can reflect the larger population.

There are websites like http://www.raosoft.com/samplesize.html that calculate the formula for researchers. If you know the amount of people in the population being studied and the level of accuracy the researchers wanted, you can roughly estimate if the researchers gathered information from enough people. For example, if I wanted to test a hypothesis about a population of 2 250 people with a CI=95% (and was pretty sure that people would respond to the questions), I would have to get data from at least 134 individuals for my data to be statistically significant.

Check it out

Look at the cosmetic advertisements in glossy women's magazines – and especially those for anti-wrinkle or anti-ageing cosmetics. Very often, the advertisement will headline, dramatically, something like "80% of women report younger-looking skin!" But somewhere in the advertisement, usually in very tiny letters, will be the detail of the case study. And this will be a very small number of women over quite a short period of time. Beware of information that parades itself as 'scientific', with displays of dramatic statistics, unless you can access the information about that research as we've described above.

Investigating health issues: finding information and sources

Story ideas

Local communities are a good place to start looking for information on what is a health problem. People are often aware of their own health problems – and may see them in a very different way from government and other organisations. Take an area suffering from chronic diarrhoea (often caused by infected water). You might find that the government sees the problem as caused by people not using the drop toilets it provides. But when you ask the local community why they do not use the government toilets, you are told that it is because the toilets are on the other side of a major highway with no easy way to cross. People are more willing to live with diarrhoea than risk injury or death every time they need to use the toilet.

Community health and education centres (like libraries, or clinics), or village health care workers are other good places to look for information and sources. Regional branches of government and organisations working in a specific area will have a list of health priorities that can help identify stories. However, government and organisations (especially large or international ones) may have priorities that do not reflect the issues of local communities. This is partly because health is usually not the first concern of people who are struggling to survive from day to day. Keep in mind that you may also have different views on what health means.

Information about the science

Basic sources of information about biomedical issues are also found in peer-reviewed publications. (These are most useful when you have a topic and are looking for further information.) Peer-reviewed publications are journals on different health subjects. They only accept research that is reviewed by other researchers and considered valid or important. Here are three online resources (in English) that are good places to start looking for peer-reviewed information:

- The Cochrane Collaboration (www.cochrane.org) is a grant-funded, independent organisation promoting evidence-based health care. The Cochrane reviews are a great place to start looking for information on a clinical topic. This is a large database of peer-reviewed and systematic review papers that the library has commissioned on certain subjects, as well as existing peer-reviewed systematic reviews.
- PubMed (www.ncbi.nlm.nih.gov/PubMed/) is a US government search engine on health topics. It searches journal and news articles. However, PubMed often only searches US publications.
- The Trip Database (www.tripdatabase.com) is a search engine that specifically looks for evidence-based research on health. It has a useful section called "Patient information Leaflets" that lists the recommended ways to use biomedical treatments. You can also look for information on specific health topics.

Investigating health issues: evaluating information

Very few health problems are new. Communities, governments or researchers may say that an issue is completely different from anything else that has happened before, but this is usually not true. Health problems are the result of many factors. Often a similar problem has come up before in history. The first thing you should do with any health problems is look at its context.

If the media's just discovered it, does that mean it's new?

Recently an article in the South African press excitedly ran a story on "Lazarus drugs" that dramatically improve the health of people who are very ill from Aids-related conditions. The story was based on a recent biomedical study that followed the long-term health of people taking antiretroviral medications. But these medications are *not* new. Antiretroviral therapy for HIV infection has been around for over 20 years and we already know it works.

Points of view about health

The information you collect on health issues is always influenced by the point of view of the person or organisation providing that information. If you are comparing biomedical data with information from a traditional healer, then make clear to your readers the context and viewpoints of each idea about health. A traditional healer often explains the same health issue in very different terms to a biomedical researcher.

Reporting on the use of non-biomedical treatments for HIV infection often has this problem. Some traditional healers claim that their medicines work because the patient stops feeling sick and the symptoms of illness go away. To the traditional healer this means the HIV is 'cured' – if the symptoms are gone then the HIV infection is gone. But when biomedical researchers test those patients who traditional healers claim to have cured of HIV infection, they say the patients are *not* cured. Biomedical tests show the HIV infection is still present in every patient's immune system, even if a patient has no obvious symptoms of illness. Both the traditional healer and the biomedical researcher are right about their claims – according to their own ideas about health and illness. (But what does the patient think, and what does the patient do?)

Is the health problem about blame?

Many health workers – both in traditional medicine and in biomedicine – end up saying that a health issue is only a problem because people did not behave in the way they were told. Governments and people with power often find it easier to blame others for a problem rather than criticise their own actions. It is very easy for a journalist to pick up and reflect this point of view without realising it.

Reporting on biomedical data

Reporting on an issue that is only biomedical – for instance a study on a new clinical medicine – means you *must* use biomedical criteria and resources. Try and find information on the existing best practice for that health issue (a research study may include this information as part of its design).

If you are reporting on a study, then look at the kind of study it is and search for any peerreviews.

Peer review and citation

Research when properly conducted and regulated as we've described above produces reliable results – even if they are more tentative, nuanced and sometimes short-term than journalists would like!

But the world of science is not free from incompetence, bias and fraud. Sometimes, research is biased by wishful thinking: someone begins an experiment or a piece of research with too fixed an idea of what is likely to result and either deliberately or even almost unconsciously pushes the results or interpretation in that direction. This is fraud.

Sometimes the sample is inadequately selected, or the research controls inadequate, or the research simply sloppily carried out.

Sometimes the research is based on mistaken assumptions.

When research is based on mistaken assumptions

"Down low" myth distorts HIV research, prevention

NEW YORK (Reuters Health) – Mistaken assumptions about black sexuality are finding their way into scientific research on the spread of HIV and this could do more to fuel risky behavior than prevent it, authors of a new commentary warn.

Reports on African-American men who identify themselves as straight but secretly have sex with men -- dubbed the "down low" lifestyle – first appeared when men who said they were part of this subculture wrote books about it and the media

When research is based on mistaken assumptions (cont.)

picked up the story, Dr. Chandra L. Ford of Columbia University in New York City, the commentary's lead author, told Reuters Health.

"Part of what has happened as a result of that initial burst of stories reporting the 'down low' is that those stories often tied the down low to high rates of HIV infection among African-American women which was not supported by epidemiological data," Ford added. "There were a lot of assumptions, there were a lot of leaps of faith that led to that."

Despite the non-scientific source, epidemiologists began doing research based on the idea that black men living the down low lifestyle were driving the spread of HIV, she and her colleagues note in their article in the Annals of Epidemiology.

This assumption was mistaken in many ways, they explain. First of all, the practice of straight men secretly having sex with men is seen across all ethnic groups.

Also, Ford notes, while black men and women have higher rates of HIV infection than other ethnic groups, they also report fewer risk behaviors, suggesting researchers should look elsewhere to understand the disparity. For example, she adds, having a bacterial sexually transmitted infection can increase the risk of both transmitting and contracting HIV, and it is possible such infections may be more common among blacks than whites due to poorer access to health care.

Research has refuted the claim that black men living the down low lifestyle are driving the spread of HIV, Ford said, but the perception that this is the case remains, even in the epidemiology community. She points to a dean at a colleague's school who urged researchers to study "the down low" after seeing a TV segment on it…

From *Scientific American*, February 28, 2007, by Anne Harding

Funding and conflicts of interest

Sometimes researchers are funded by a body with an interest in the outcome – for example, in the 1960s several studies, later discredited, were funded by the tobacco industry to suggest that smoking was not as harmful as impartial research suggested. Some US scientists have recently declared that in the 1990s the US government, which was funding their research, put pressure on them to minimise the effects of global warming, or actually edited sections out of their research reports before publishing them.

Researchers are supposed to include funding information in their publications, but sometimes do not when the funding is indirect. (For example, if the university where a researcher works has received a large grant from the pharmaceutical company that makes the medication that researcher is testing, but the money is not directly allocated to the researcher's laboratory.)

Spotting the problems

So how can a journalist, who is not a technical expert, spot these problems?

- You need technical experts in your contacts book. In Chapter 5 we discuss finding and interviewing experts, and you might like to refer back to that section for additional hints.
- You need to find out about the credentials of research bodies and individual scientists, particularly if what they say seems highly controversial or out of tune with what the majority of research suggests. This does not mean they are either frauds, or wrong. But you may discover that their qualifications are not, in fact, as strong as they claim, or that an interested party funded the research – and that should lead you to interrogate it quite closely. (Find out, for example, who the donors are to the funding foundation.) A general tracking website such as journalismnet's whois (http://www.journalismnet.com/tips/whois.htm) can provide information about individuals.

A menace to science

Call her the Awful Poo Lady, call her Dr Gillian McKeith PhD: she is an empire, a multi-millionaire, a phenomenon, a prime-time TV celebrity, a bestselling author. She has her own range of foods and mysterious powders, she has pills to give you an erection, and her face is in every health food store in the country. Scottish Conservative politicians want her to advise the government. The Soil Association gave her a prize for educating the public. And yet, to anyone who knows the slightest bit about science, this woman is a bad joke.

One of those angry nerds took her down this week. A regular from my website badscience.net - I can barely contain my pride – took McKeith to the Advertising Standards Authority, complaining about her using the title "doctor" on the basis of a qualification gained by correspondence course from a non-accredited American college. He won. She may have sidestepped the publication of a damning ASA draft adjudication at the last minute by accepting – "voluntarily" – not to call herself "doctor" in her advertising any more. But would you know it, a copy of that draft adjudication has fallen into our laps, and it concludes that "the claim 'Dr' was likely to mislead". The advert allegedly breached two clauses of the Committee of Advertising Practice code: "substantiation" and "truthfulness".

From *The Guardian*, February 12, 2007, by Ben Goldacre

- Check if the research is published in a 'peer-reviewed' scientific journal. This is any journal where articles are sent out to other experts in the field for comment and critique. It is not an absolute guarantee, but it is a very good safety mechanism for detecting badly conducted research that departs too far from methods we know work.
- Check that the journal where the work is published is well recognised. You can discover this by looking at how many 'citations' it has – in other words, how many other papers and journals refer to it. A recognised journal will have hundreds of thousands of citations every year. One with far fewer is suspect.

Numbers can be deceptive...

When South African President Thabo Mbeki began to cast doubts on the hypothesis that the HI virus causes Aids, he cited an article in what he described as "a very senior scientific journal": *Current Research and Medical Opinion*. In 2004, this journal was cited 1 148 times. In the same year *The Lancet* was cited 126 002 times; the *Journal of Immunology* 108 602 times and the *New England Journal of Medicine* 159 498 times.

Doesn't this mean that bioscience is a conservative closed circle where those accepted in the field endorse and reinforce one another and it's hard for revolutionaries to get a look-in? Absolutely! But for every genuine revolutionary there are a hundred frauds and charlatans, and your responsibility as a non-specialist journalist investigating on behalf of an even less specialist audience is to tread cautiously, and not mislead readers into health approaches that might just kill them. Don't dismiss information that doesn't fit these criteria, but check it out extremely carefully and don't overstate your reporting of it. Balance requires that you mention in your story if something has not been peer-reviewed, if a journal is insignificant or if there are questions about a researcher.

Investigating health issues: checklists for your stories

During the reporting phase

- Have you asked how, by whom, where, with how many subjects and when the research was conducted?
- Have you asked about controls on a test?
- Have you asked about ethics, and information given to patients/subjects?
- Have you asked how 'certain' the results are?
- Have you asked about issues such as the placebo effect?
- Have you compared and contrasted what you are reporting with what other experts in the field (including regulatory bodies) say?
- Have you investigated whether other interpretations of the data are possible?
- Have you checked your own understanding with technical experts who can illuminate complex aspects?
- Have you looked at who the role players are and where their funding came from?
- Have you investigated context and cultural factors?

During the writing phase

- Are you absolutely clear what the story is about? Could you explain it to a friend or member of your family, briefly and in non-technical language?
- Have you written it as clearly and simply as you might explain it in speech? Remember: readers are even less specialist than you are.
- Have you avoided sensationalism and loaded language? Be especially careful with terms like 'cure', 'breakthrough' and 'miracle'. They rarely are.
- Have you included the relevant context information?
- Have you made the investigation human, by including live-voice quotes and the stories of real people?
- Have you relayed facts and figures absolutely accurately (and double-checked them with their source)?
- Are you going to stay with the story until it is on the page? Good health and science reporting can be wholly undermined by the spin created in headlines and other editing. Have the confidence to discuss with subeditors any story treatments that you feel could undermine or distort your message.

Misleading headlines can ruin a story

"Tainted Drugs Linked to Maker of Abortion Pill"

This headline appeared on a *New York Times* story in January 2008 about contamination at a drug factory in China. The factory was owned by the makers of a controversial abortion drug, mifepristone – but the factory making mifepristone was an hour's drive away from it and there was no evidence of any problems at that site. Maybe the subeditors were seeking to make the story more 'newsy' by linking it with a drug that had already featured prominently in other headlines? The problem is, many readers – whom we know skim headlines far more often than they read stories – might get the mistaken impression that mifepristone was dangerously contaminated.

Investigating health issues: reporting on health when people are afraid, ill-informed or resigned

People are often afraid of health conditions. There are many reasons for this: sometimes the illness is known to cause death, or it is painful, or the person's society believes having the condition means something about the person who has it. Negative associations or ideas about a health condition are referred to as stigma (like HIV-related stigma and disability-related stigma). Look at Chapter 5 for information about how to interview reluctant and traumatised people and help them to tell their stories.

Many of the most common health conditions in people's lives are hard for journalists to report on because of stigma, lack of information or resignation. Journalists hold a special position in society because news is one of the main ways most people learn about health conditions.

When thinking about denial, it is important to think about people's social situation. Gender may be an important factor in people's attitudes. Women in traditional societies are often expected to obey men, and may be stigmatised or punished if they step outside that role – for example, by speaking out about a personal or family illness.

Other social factors can also silence people or limit their health choices. Poverty disempowers people, not simply because they cannot afford medications, but also because they often cannot afford simple things like transport, which would give them access to treatment and counselling. The desperation of poverty can lead people into unwise lifestyle choices, such as entering sex work. One UN survey in East Africa found that the majority of girls who attached themselves to 'sugar daddies' did so not for luxuries such as jewellery or cellphones, but for money for school uniforms and books for themselves and their siblings, or to buy food for their families.

Stigma also disempowers people. Prejudice and discrimination feed people's sense of hopelessness, making them feel there is no point in seeking treatment or changing their lifestyle.

For this reason, your reporting needs always to contexualise the health issues you write about, and include consideration of broader social issues that impact on the story.

Know the basics

A journalist reporting on a health condition must always know its basic issues. These are:

- How does a person develop this condition? How do people believe it develops? Is it transmitted from another person? How does that happen? Is it environmental or work-related? Why?
- Can a person prevent this condition? How? Is prevention easy or hard? If an individual cannot avoid the problem, is there another way of preventing the issue?
- How do we know if a person has the health condition? Is diagnosis through a test or made only when a person has symptoms?
- Is there treatment for this condition? Do we have any evidence that a treatment works?
- Is this condition something that develops fast (acute) or does it take a long time (chronic)? How does that affect treatment?
- How serious do people think the problem is? Is there a possibility of death or disability? What level of disability might occur?
- What contextual factors (gender, poverty, power, stigma, status) are relevant?

This sounds like a lot of information, but it is usually simple to find. A good place to start looking is the WHO site (www.who.int).

Make sure you know the relevant facts

Ebola is an infection that makes a lot of people very scared. People want to know about it, so journalists write about it. It is very important that a journalist writing about Ebola knows that:

- Ebola is only transmitted if a human has direct contact with infected organs and body fluids like blood.
- A person can prevent infection with Ebola if the infected body fluids are avoided, or if barriers (like gloves) are used.
- We only know if a person has Ebola when they get severe symptoms. Most people are infected with Ebola for 2 to 21 days before they get any symptoms.
- There are five types of Ebola. Only four types cause illness. Death rates are about 50% to 90% of symptomatic patients, depending on the type of Ebola.
- People are very scared by Ebola because of its high death rate and because anyone can be infected without knowing they have it.

This information is from the WHO factsheet on Ebola.[11]

Addressing stigma

Negative associations about a health condition can be so strong that they stop people accessing available treatment and care services. A stigmatised condition that is transmitted between humans will spread when people are too afraid to find out if they have the condition or admit to any symptoms. Sometimes a person will not even try to prevent infection if it is seen as a sign that the person has reason to worry about infection.

HIV-related stigma is usually found in communities that do not know as much as they think they do about HIV infection. People who are afraid of HIV infection almost always think that Aids is an acute infection that always leads to death. They worry that they cannot protect themselves from infection (and often see protection as only the responsibility of people who know they are HIV positive). Some communities view a person living with HIV infection as "bad", believing that the HIV-positive person has made choices that the people passing judgement think they could never make. These same people usually have resources that mean they never have to think about making those choices.

Stopping HIV-related stigma has three key elements. People must know that HIV infection is not a death sentence (though it is a chronic condition that can lead to life-threatening Aids). Information on the simple ways to protect against infection must be available to everyone. Lastly, being infected with HIV is more about the kind of choices and resources a person has or wants in his or her life than it is about whether those choices are "good" or "bad".

Dealing with a lack of information

People are afraid of the things they do not understand. Sometimes governments, organisations and health care workers do not give enough information about a health condition that they claim is a problem. This can make the problem worse, especially if people are told it is a very serious health issue.

In the last 10 years governments and other organisations have become very worried about two new kinds of tuberculosis (TB). Both these conditions – multi-drug resistant TB (MDR-TB) and extremely drug resistant TB (XDR-TB) – are the result of biological resistance to the common medications used to treat TB infection. MDR-TB and XDR-TB need more expensive drugs for longer periods of time than first-line TB treatment.

Patients diagnosed with XDR-TB in South Africa are now confined to hospitals for most of their treatment (this is at least 6 months and possibly two years). The patients cannot leave the hospital, are allowed very few visits from their family, and cannot work. They are told they will probably die of the XDR-TB. Some try to escape and go home. The government tells the public that these patients are "dangerous" (sometimes even using crime-related phrases like "on the run" about them!), saying that the XDR-TB makes them highly infectious.

But there is no evidence that XDR-TB is more infectious than normal TB – though it is harder to treat. Treating a person with XDR-TB as a highly infectious danger to the general public is medically wrong. In addition, many patients with XDR-TB are unlikely to be able to transmit the TB infection. Most people know that TB can infect the lungs. What most people do not know is that TB can infect any organ or tissue in the human body, but it is only transmitted through droplets of saliva in the air expelled from a person's TB-infected lungs by coughs, spitting or sneezes. Most patients with XDR-TB are also infected with HIV. About half of all TB infections in HIV-positive patients are non-pulmonary (not in the lungs) and cannot be transmitted by coughing or sneezing.

Reporting on a 'normal' health condition

Sometimes a health condition is considered normal – the people who are affected by it are resigned and do not expect the situation to get better. Often affected communities lack the resources to make changes, or to even ask for help.

Malaria is an infection that is found in many parts of Africa and Asia and transmitted through mosquito bites. Common symptoms of malaria are a high fever, headache, vomiting, and feeling very tired for a long time after the fever. Every year about 500 million people get very ill with malaria. About 10% of pregnant women who get malaria will die. Malaria also affects child development and local economies.[12]

For many communities in affected areas, malaria is considered a normal part of life. Most people will be infected as children and have episodes of malaria throughout their lives. Governments do not usually have special resources that are only for malaria. Some organisations provide barrier mosquito nets and treatment, but most people affected by malaria get no help. It is very important to constantly remind both affected communities and organisations with the power to allocate resources that malaria is a problem that can be prevented and treated.

Case studies

Case study The Emtri story by Finnigan wa Simbeye

Tanzanian journalist Finnigan wa Simbeye found himself having to deal with both technical information about a drug and the politics of medical treatment when he began reporting on the case of the antiretroviral medicine Emtri.

How did you get the idea for the story?
The first story was actually brought to me by some junior officials at Medical Stores Department (MSD) in Tanzania after people who were on Emtri medication complained about serious side effects.

What happened when you reported this?
When I first did the story last year, the government dismissed the allegations and said that, in fact, out of over 43 000 people using Emtri ARV only three reported serious side effects. But when I visited some individuals using the drug, they would only complain secretly, fearing reprisals from health officials because the supplier had very close relationships with the officials.

How did you go about the reporting and what resources did you use?
I got a list of WHO approved ARVs, some Emtri purchasing documents from MSD and I talked to the minister, the permanent secretary at the Ministry of Health, the manufacturer, Emcure Pharmaceuticals of India and the Global Fund, and to WHO through e-mails and phone calls. I did use the Internet a lot to search for Emtri, Emcure, WHO, and the Global Fund to get facts on the subject.

What happened when the story appeared? What problems did you encounter and how did you deal with them?
I really got in trouble when Emcure threatened to take us to court for mudslinging their ARV cocktail, the permanent secretary at the Ministry of Health also threatened to sue us while the country's largest referral hospital, Muhimbili National Hospital also threatened to sue.

I had to start looking for extra evidence to pin individuals to corrupt relations with the supplier and investigate more on the scandal which helped us run more follow-up stories until when Tanzania Network of People living with HIV/Aids chairman Julius Kaaya finally went public to denounce Emtri and advise his members to stop using it. There was also an attempt by Emcure to bribe us and stop publication of the story.

How long did the story take you?
The first investigation took over three months and later follow up stories earlier this year took another two to six months.

What were the results?
The matter reached parliament and the minister ordered suspension of the ARV until a study is done to find out why people using Emtri reported deteriorating CD4 counts, loss of weight and lack of appetite. Of course after Mr Kaaya went public, all local papers carried the story and focus was on why the government bought an ARV which was not pre-qualified by WHO contrary to regulations. The permanent secretary and several Ministry of Health officials lost their job or got retired or shifted to other sections of the ministry.

Finnigan's story reinforces several points made in this chapter.

- If he had not investigated outside his national context and developed some understanding of the status of the drug, he could easily have accepted the Ministry's assurances that complaints were not significant.
- If he had not looked at context (the generally corrupt relationship with drug suppliers) he would not have been able to deal with the reasons for the problem.
- And if he had not used good interviewing skills to give the story a human face and help an activist go public about the effects of the drug, it would not have had such an impact at both popular and government level.

Key points from this chapter

NOTE: while much of the information in this chapter has focused on HIV/Aids and TB, because these are highly topical issues, we hope we have provided you with approaches and hints that you can apply to any other health issue on which you report. In the bibliography you'll find sites dealing with other common African health problems including malaria and cholera.

- **People can have very different ideas about what health and illness mean.**
- **Traditional ways of understanding health and medicine interpret a health issue in terms of society, but biomedicine interprets the same health issue only in terms of an individual's body.**
- **Most international health bodies use biomedicine to evaluate health issues.**
- **Biomedicine is based on the idea of objective, measurable research that is used to create 'best practice' guidelines for treating health conditions.**
- **There are different kinds of biomedical research. Each kind of study looks for information in a slightly different way.**
- **Clinical studies are an important way that biomedicine gathers information. Each phase has clear steps to it.**
- **Published biomedical research is a good place to look for stories, but the journalist must always ask why this topic was chosen for research.**
- **If a story is about biomedical research then the story must be evaluated using biomedicine's own criteria (like good study design).**
- **Finding out the basic information about a health issue before reporting on it is simple but important.**
- **Stigma, lack of information and resignation about a health problem are important issues that journalists can help to solve.**

Glossary

Terms used in biomedical research

- **Acute** – When symptoms of a health condition quickly appear and/or last a short period of time. Acute does **not** mean severe.
- **Chronic** – When symptoms of a health condition last a long period of time (usually more than three months) or when the same condition occurs more than once.
- **Confidence Interval or Confidence Level (CI)** – A term used in statistics. Used to indicate how reliable an estimate is in statistical terms. If a researcher throws a CI range into the conversation, ask them to explain what significance that specific range has for the reliability of the study.
- **Diagnosis** – The process of identifying a health condition. This can be done by looking at symptoms and/or by using a test. Most conditions have a biomedical 'diagnostic criteria' (a combination of symptoms and sometimes test results) that guides diagnosis.
- **Endemic** – When an infection is normally present at a stable level in a human population. (This can be at a very high level.) Malaria is endemic in many parts of Asia and Africa.
- **Epidemic (and pandemic)** – When large numbers of cases of an infection unexpectedly appear in a large population. If it happens in a contained locality it is sometimes called an outbreak. If the cases appear in an area that stretches over more than one national border it is referred to as a pandemic.
- **Half-life of a medication** – The amount of time it takes for a medicine to decrease to half its strength after being taken by a person. This is a way of measuring how long it takes for a medicine to be absorbed by a person's body.

Glossary (cont.)

- ***In vitro* testing** – When an experiment is performed in a controlled environment and not in a living organism. This usually means in a laboratory.
- ***In vivo* testing** – When an experiment is performed in a living organism. This refers to animal testing or clinical trials in humans.
- **Incidence and Prevalence** – *Incidence* is the number of new cases of a health condition that occur within a specific *period* of time. This is different from *prevalence*, which is the total number of cases of a health condition at a specific *point* in time. Incidence can illustrate the risk of contracting a health condition. Prevalence illustrates how common the health condition is in a population.
- **Margin of error** – A term used in statistics. It indicates the amount of random sampling error that may occur in a survey or study. However, margins of error do not reflect any systematic errors in the study (e.g. non-response).
- **Sensitivity** – A term used in medical statistics. A measure of how well a diagnostic test correctly identifies the people who have a specific health condition. (Sometimes called a measure of 'true positives'.) Ideally a diagnostic test will have nearly 100% sensitivity with no 'false-positives'.
- **Specificity** – A term used in medical statistics. A measure of how well a diagnostic test correctly identifies the people who do NOT have a specific health condition. (Sometimes called a measure of 'true negatives'.) High specificity is important in ensuring there is a low rate of 'false-negatives'.

Further reading

There are many websites, books and academic journals that provide information on health. The list below is a good start:

1 Writing about Health (for Journalists)

Bad Science

- Weekly column written since 2003 by Ben Goldacre and published in *The Guardian*. Reviews a variety of health-related science topics in terms of scientific reason and journalistic coverage. http://www.guardian.co.uk/science/series/badscience
  (http://www.badscience.net/ also lists the articles and has a list of recommended books on the science of health.)

The seven words you shouldn't use in medical news

- Article by Gary Schwitzer (2000) discussing why the words 'cure', 'miracle', 'breakthrough', 'promising', 'dramatic', 'hope' and 'victim' should not be used when reporting on health issues.
  http://www.tc.umn.edu/~schwitz/The7words.htm

Beyond cures, breakthroughs, and news releases: Ideas for covering health & medicine

- Article by Gary Schwitzer (2005) calling for journalists to look beyond the hype for 'new' medical treatments or breakthroughs. http://www.poynter.org/dg.lts/id.78806/content.content_view.htm

2 General health information

World Health Organisation

- Provides updated and peer-approved biomedicine-based guidelines and criteria for all major health conditions.
  http://www.who.int/
  (Factsheets on most common health conditions can be found at: http://www.who.int/mediacentre/factsheets/en/)

National Institutes of Health (NIH) consumer site

- US government organisation that provides research and information on biomedical health concerns. The information is clearly and concisely written for health care consumers.
  http://health.nih.gov/

Further reading (cont.)

Medline Plus
- Another NIH site. The site allows you to search for health-related information from organisations, the US government, and academic journals. Information is provided for both patients and health care providers. It does tend to focus on US-based information. http://www.nlm.nih.gov/medlineplus/

SA Health Info
- A new service provided by the South African Medical Research Council. Peer-reviewed and evidence-based biomedical information is available for the southern African region.http://www.sahealthinfo.org/

The Cochrane Collaboration
- An independent organisation promoting evidence-based health care. Provides a database of peer-reviewed and systematic review papers on some health subjects. http://www.cochrane.org/

PubMed
- A US government-run search engine covering most health topics. It searches journal and news articles. However, PubMed often only searches USA publications. http://www.ncbi.nlm.nih.gov/PubMed/

The Trip Database
- A search engine for evidence-based health research. Provides 'Patient information Leaflets' for many biomedical treatments. Search engines are also available for specific health topics. http://www.tripdatabase.com/

ClinicalTrials.gov
- This US-based site is a registry of US-government and private clinical trials around the world. Contact details are also available for most trials. http://www.clinicaltrials.gov/

Medline Plus Medical Encyclopaedia
- Part of the US government Medline site. It has information on health conditions, treatments, diagnosis and prevention, as well as medical photographs and illustrations. http://www.nlm.nih.gov/medlineplus/encyclopedia.html

NHS Direct Health Encyclopaedia
- Provided for patients by the UK National Health Service. Information on health conditions, treatments, diagnosis and prevention can be found either by topic or by using the interactive body guide. http://www.nhsdirect.nhs.uk/encyclopaedia/

Merck Manuals Online Medical Library
- Free online version of one of the most comprehensive biomedical manuals in print. Health care provider-level information is written in plain English. http://www.merck.com/mmhe/index.html

3 Information on HIV/Aids, Tuberculosis and Malaria

AIDS Infonet
- Provides regularly updated treatment information for HIV and HIV-related health conditions. http://www.aidsinfonet.org/

AVERT
- A comprehensive website with referenced information on HIV-related topics by issue and country. http://www.avert.org/

AIDSInfo
- A US government service provided through the NIH that lists the latest on HIV-related treatment, prevention and research. It has a section that lists approved HIV-related clinical trials: this can be searched by country. http://www.aidsinfo.nih.gov/

nelsonmandela.org
- The Nelson Mandela Foundation provides information related to HIV/Aids and initiatives to tackle the pandemic in South Africa.

Further reading (cont.)

Journaids.org
- Provides stories, reporting hints and tipsheets.

SAHARA: Social Aspects of HIV/AIDS Research Alliance
- A South African-based organisation that provides information and links on non-medical aspects of HIV/Aids.

http://www.sahara.org.za/

WHO Global Tuberculosis Database
- Official country-level information on tuberculosis can be searched by category, topic, geographical area, and time period. http://www.who.int/globalatlas/dataQuery/default.asp

Malaria Journal
- This is an Open Access peer-reviewed academic journal on malaria. http://www.malariajournal.com/home/

Voices for a Malaria-Free Future
- The site is aimed at policy-makers and provides information on successful malaria treatment programmes with evidence-based results. http://www.malariafreefuture.org/

Malaria Foundation International
- A non-profit organisation with overviews of the malaria life cycle, as well as information on initiatives across the world to combat malaria. http://www.malaria.org/

4 Information on Endemic Diseases found in Poorly-Resourced Areas

Cholera (CDC)
- Accessible, general information on cholera (with a U.S. focus), and links to more technical information. http://www.cdc.gov/nczved/dfbmd/disease_listing/cholera_gi.html

Tropical Diseases (WHO)

Provides a list of the main tropical diseases, such as African trypanosomiasis and Leishmaniasis. Each disease has a link to WHO
- general and specific information on the condition. http://www.who.int/tdr/diseases/default.htm

PLoS Neglected Tropical Diseases
- Peer-reviewed, open-access journal that provides the latest information on diseases that are often endemic in poorly-resourced areas. Most articles are highly technical. http://www.plosntds.org/

5 Information on Traditional Medicine

SA Health Info: Traditional Medicine
- Southern African traditional medicine information and links are provided through the SA Health Info site. http://www.sahealthinfo.org/traditionalmeds/traditionalmeds.htm

Traditional Medicine Research Institute (Sudan)
- The Sudanese government provides this site to ensure "the study of traditional Sudanese health care systems." http://www.sudan-health.net/

Indigenous Knowledge Program
- A World Bank project, the site is development-orientated and looks at community-based practices. A monthly publication – IK Notes – provides information on a variety of health and development subjects. http://go.worldbank.org/CFZJDCEDM0

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