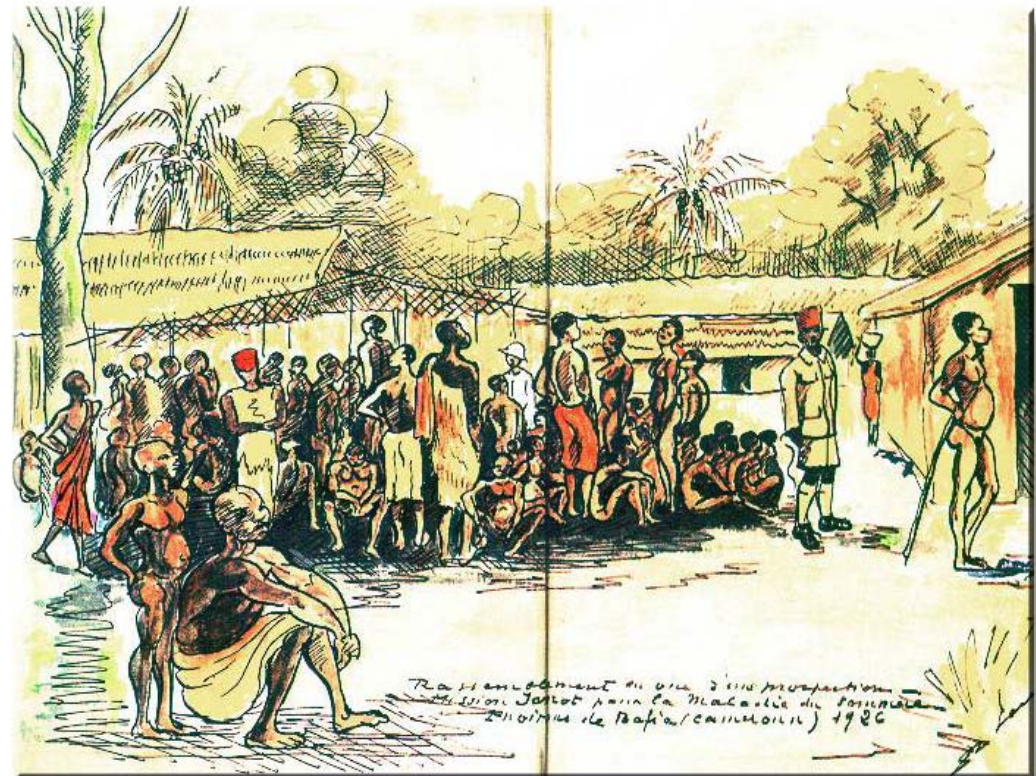


## Sleeping sickness – The controversy continues

Dr Jean Jannin

Neglected Tropical Diseases Control  
Innovative and Intensified Disease Management

**“Man and his species are in perpetual struggle with microbes, with incompatible mothers in law, with drunken car-drivers, and with cosmic rays from outer space....”**  
I. Gordon. *The Lancet*, 1958



## Origins



Berlin treaty 1885 allows colonial countries to rush inside central Africa.

A few years after they had to face a new killing disease: sleeping sickness.

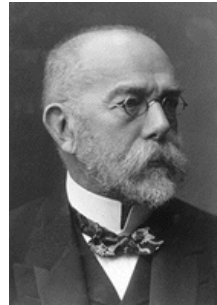
- Fear of facing a continent empty of all manpower
- Great commitment of politicians, scientists, physicians.
- Allocation of needed funds



Louis Pasteur



Paul Ehrlich



Robert Koch

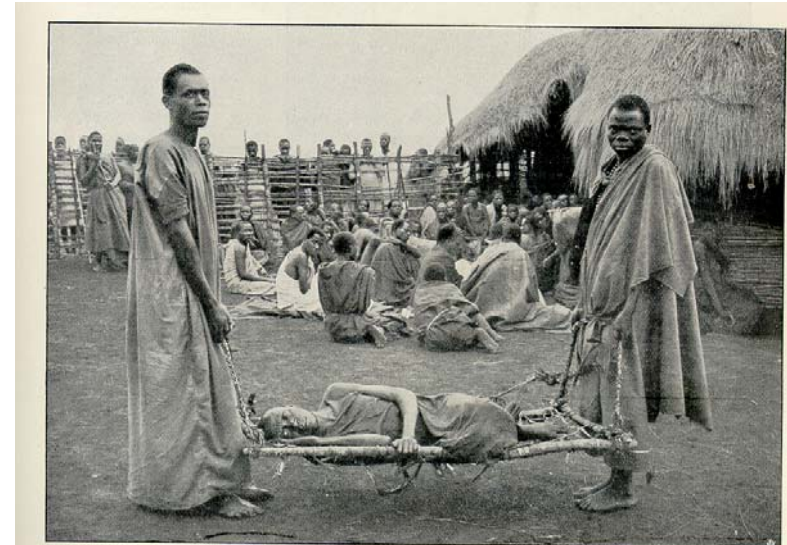
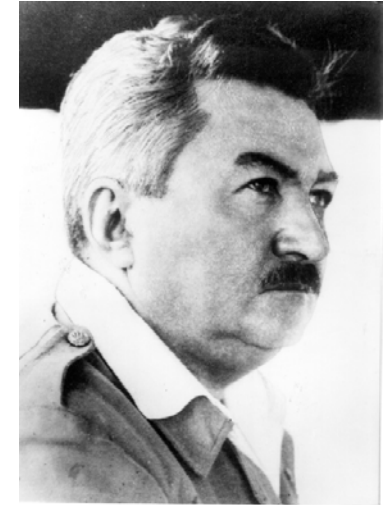
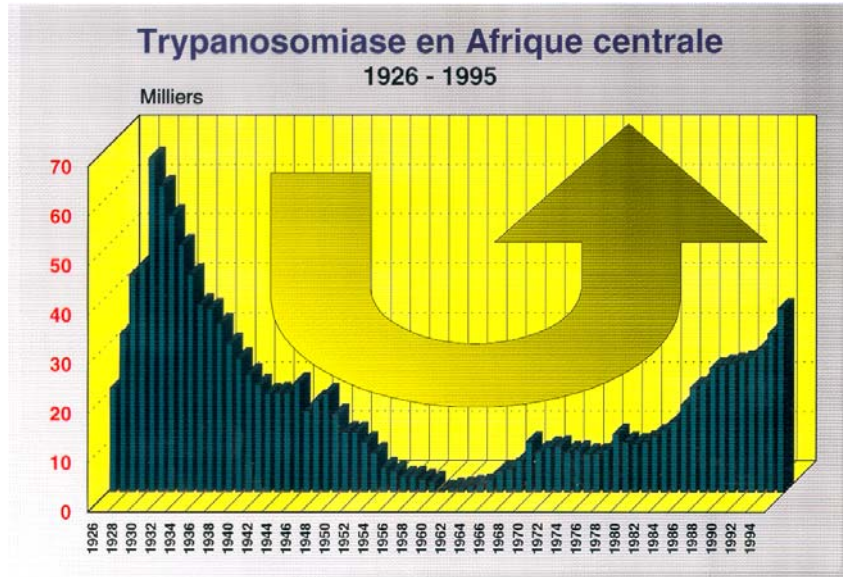


Fig. 53 und 54. Kranke in improvisierten Tragbahren.

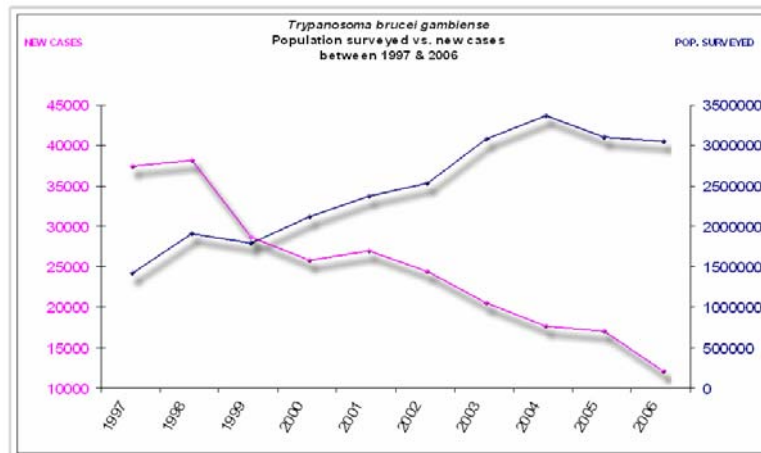
## Learning from the past.... Coming from far... The golden age?...



Eugène Jamot

- Jamot's rules
- Systematic screening and treatment

It has become commonplace to say that trypanosomiasis is almost eradicated in Africa.... Although foci are relatively rare, they are nonetheless irritating..  
Labusquière, 1965



## Learning from the past.... Coming from far... The golden age?...

- Elimination of HAT in the 1960s
- Elimination of yaws
- Elimination of kala-azar
- Elimination of malaria
- Elimination of shistosomiasis

**WHAT ARE OUR A SHORT HISTORY**

**1948** When diplomats met in San Francisco to form the United Nations in 1945, one of the things they discussed was setting up a global health organization. WHO's Constitution came into force on 7 April 1948 – a date we now celebrate every year as World Health Day.

**1948** Delegates from 53 of WHO's 55 original member states came to the first World Health Assembly in June 1948. They decided that WHO's top priorities would be malaria, women's and children's health, tuberculosis, venereal disease, nutrition and environmental sanitation – many of which we are still working on today. WHO's work has since grown to also cover health problems that were not even known in 1948, including relatively new diseases such as HIV/AIDS.

**1952** Dr James Sak (US) develops the first successful polio vaccine.

**1952–1964** Global yaws control programme. One of the first diseases to claim WHO's attention was yaws, a crippling and disfiguring disease that affected some 50 million people in 1952. The global yaws control programme, fully operational between 1952–1964, used long-acting penicillin to treat yaws with one single injection. By 1965, the control programme had examined 300 million people in 46 countries and reduced global disease prevalence by more than 95%.

**1967** South African surgeon Christian Barnard conducts the first heart transplant.

**1974** The World Health Assembly adopts a resolution to create the Expanded Programme on Immunization to bring basic vaccines to all the world's children.

**1977** The first Essential Medicines List appeared in 1977, three years after the World Health Assembly introduced the concept of "essential drugs" and "rational drug policy". 156 countries today have a national list of essential medicines.

**1974** Onchocerciasis control programme. WHO worked for 30 years to eliminate onchocerciasis, or river blindness – from West Africa. 600 000 cases of blindness have been prevented and 18 million children spared from the disease. Thousands of farmers have been able to reclaim 25 million hectares of fertile river land that had been abandoned because of the risk of infection.

4 WORKING FOR HEALTH: AN INTRODUCTION TO THE WORLD HEALTH ORGANIZATION

## Why such a huge collection of failures?

Elimination was considered as a new definitive status of diseases and not as a permanent process to be maintained and adapted over time

- Is the problem that activities have been abandoned?

or

- that the same activities continued to be performed?

- Do we have the capacity to adapt public health policies to realities?
- Can we assume that the problem was a continuation of doing the same, when the conditions were different and the support of society (politicians and the general population) was lost?



## Concept of sustainability

Initiated by Gro Harlem Brundtland(1).

The concept does not arise from a phase of scarcity or from problems, but from a period of abundance and successes, which means that it is clearly related to success.

When there are problems and scarcity, there is no problem of sustainability but rather one of self-improvement.

**The hypothesis is that the collection of failures which happened in the past could be prevented if the sustainability concept **is timely and everlastingly** associated with the control/elimination process. Many obstacles must be overcome.**

## **Obstacles to sustainability**

### **The punishment of success**

- Governments are re-assessing priorities in light of the relative burden and therefore do not provide more support and ultimately withdraw resources;
- National programmes or capacities are weakened or dismantled due to the reduction of activities;
- Knowledge and expertise are also becoming low with no consideration of replacing previous trained human resources;
- No incentive is provided to encourage research and development;
- The attraction for scientists/MDs to go towards new fashioned disciplines instead of old fashioned (entomology vs molecular biology) leads to a lack of trained people in endemic areas.
- NGOs are leaving or moving to other areas because of the reduction of cases;

## Obstacles to sustainability

### Fear of change

- The risk of believing that success is permanent and that it is unnecessary to adapt is a strong predictive determinant in sustainability failure.
- Is it satisfactory to continue with the same programmes under conditions of low infestation and low incidence?
  - A lack of holistic vision
  - A wrong process of decision making (succession of small and exceptional decisions)
  - Not a timely process
  - No innovation (changing the vision)

## Obstacles to sustainability

### The "tyranny of small decisions"

Alfred Kahn shows how decisions that are small in size, in a time perspective, and in relation to their cumulative effect may lead to suboptimal resource allocation.

It has been extended to the concept of how logical micro motives could lead to a wrong macro behaviour.

- Absolute necessity of having a broad vision of the problem to be solved and to put it in perspective over time.
- Public health actions and management of programmes must be developed within a broad strategic vision and not managed in a day-to-day problem solving approach.

## Obstacles to sustainability

### The notoriety bias

- Some problems or facts are over-represented leading to an effect very similar to fashion. Priorities are too often defined in comparison with their visibility. Which means that good advocacy can lead to a strong awareness introducing a big bias in the decision making process.
- "We need to look at our priorities in a more objective, analytic way, free from the understandable inertia of yesterday's activities and fashions<sup>[1]</sup>.
- There is a disequilibrium of the representativeness in many groups in charge of examining problems and giving advice. Due to their high visibility, high-level scientists are often over-represented and their role of experts is overtaking the role of the decision makers or of the public health specialists. Too often, heads of programmes or health authorities (in charge of implementation policies) are not represented in these fora.
- Very often, notoriety associated with the capacity of raising awareness and funds is introducing a large bias in decision making for defining strategies and implementation of programmes against diseases.

## Obstacles to sustainability

### The tyranny of DALYs

- Diseases like sleeping sickness, Buruli ulcer, yaws, leishmaniasis or Chagas disease are focal diseases.
- What means BoDs and DALYs for focal diseases?
- HAT in DRC and leishmaniasis in Sudan.
- Generally, efforts for controlling/eliminating these diseases are rewarded by a growing disinterest from authorities and influential pressure groups, leading to drastic reduction of resources and incentives to develop new tools.
- Development of new indicators (ethics-based analysis).

## **Interaction of science, politics and decision making for innovation and sustainability**

- It is important in the public health area to have an idea on how science and politics are linked and interact.
- Experts (mainly in science area) should provide technical answers to specific questions. More widely, they should provide evidence.
- Decision makers and by extension politicians should use the decision analysis based on many factors and not only on evidence and technical facts.
- Sometimes, they need to ask science to fill in the gaps.
- As soon as new knowledge arises, it contributes to incorporating more evidence into public policies through decision making and implementation bodies.
  
- A lot of social, environmental, political, economical and personal feelings contribute to the decision. Generally, non-technical arguments are prominent in decision making.

## Science and politics approaches

There are two components in decision making: science and politics.

Max Weber (1), by introducing the concept of rationalization in early 1900s, made possible the distinction between actions driven by laws of nature, demonstrated by science, and what's belonging to politics

### Science and the "ethics of conviction"

Science mainly aims at providing evidence and new tools. Science is supposed to play the role of the expert answering specific questions in order to feed the decision analysis:



Max Weber

- I do what I believe in without giving any importance to the consequences, which means that science is driven by an "ethics of the truth"

### Politics and the ethics of responsibility

Politics and decision making aim at defining and applying the safest and the most acceptable new policies for all. It is clearly related to sociology and management.

- I am responsible for what happens with my acts, which means that politics is driven by the "ethics of responsibility"

[1] Max Weber (1919). Le savant et le politique. This book is issued from two conferences delivered by Max Weber: the profession and vocation of scientists (Wissenschaft als Beruf) and the profession and vocation of politicians (Politik als Beruf.)

## **Sustainability: bridging the gap between science and politics**

Sustainability implies the encounter of two practices, the scientific and the political with their particular vocation and craft.

It must be:

- The encounter of the two ethical positions
- The encounter of two types of products: knowledge and decisions

Linking normative role, technical guidance, decision making and implementation

## Improvements

### Decision making

Decision making in a public health context is a very complex process

- Decision is different from choice
- As decision making is the result of a large set of arguments and feelings, it cannot be totally evidence-based. Hirshman<sup>[1]</sup> is saying: "i) Men and decision makers never know very well what they want, ii) They are discovering their goals, often new goals, through their experience, which means their decisions."
- What is the weight of technical inputs?
- Relationship with other factors (all other determinants)
- Is evidence an isolated factor into decision?
- Who needs evidence based demonstration? Is it requested by decision makers or is it promoted by researchers?

<sup>[1]</sup> Hirschman A. 1967. Development projects observed. Washington. Brooking Institution

## Improvements

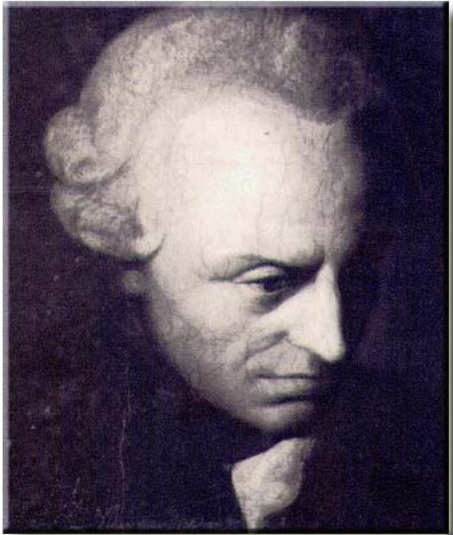
### The concept of sustainability of elimination activities for neglected tropical diseases

It is useful to respond to the first question:

- *Is what we have achieved permanent?* The answer is clearly no! Which means that we need to permanently keep in mind the second question:
- *How can we make what we have achieved permanent?* This question is raising the issue of sustainability of what has been achieved.
- *Do the same activities carried out to achieve success, serve to maintain it?.*
- *Is it necessary to do something different?* Yes.
- *How to do something different?*

## Our responsibility

- Doing something different implies thinking differently!



Emmanuel Kant

### SAPERE AUDE!

A new way of thinking and to follow what Kant (1788) launched as a great goal of modern knowledge: ***dare to think!***

Motto of the enlightenment

## Our responsibility

"Trespassing is often used in a negative sense in the United States: For example, in notice boards that say "No Trespassing", viewing it as a violation of private property, but in my view it can have a positive value: it can mean stepping over the borders between one discipline and another, without seeing them as rigid divisions" (1)

- Is sustainable elimination of diseases a dream?

The elimination of the neglected diseases and the sustainability of the achievements after having been attained require our imagination and our boldness. It is expressing the wish to move our mind from routine and comfort to new horizons.

- Take care of not dreaming

"Big organizations are characterized by strong inertia which leads to the fact that, except if a rupture occurs, changes will unavoidably take a long time to happen, which implies that these changes should have been prepared a while ago".  
(Crozier)

Taking known paths doesn't lead us to  
unknown places