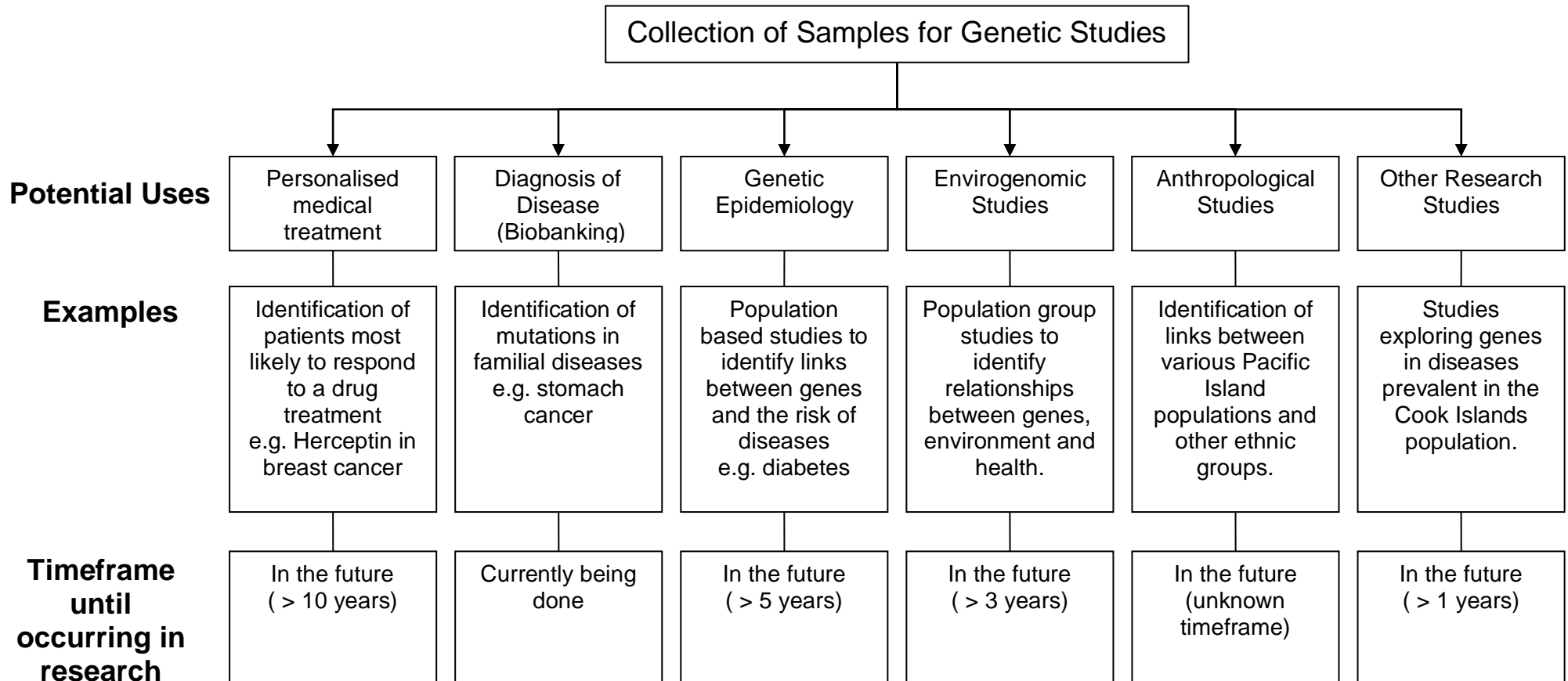


Framework for Conduct of Human Genetics Studies in Cook Islands

Introduction

Framework for Conduct of Human Genetics Studies in Cook Islands



- Need for community consultation on any proposal to involve the Cook Islands population in gene studies. NB Likely that the Cook Islands population in New Zealand may participate in many of the studies identified above.
- All studies would need review (primary review and external technical advice) and the Cook Islands Research Committee.
- All studies would require ethical approval (and external expert advice).
- Where relevant, issues related to indigenous peoples' rights would need to be addressed.

Different types of Genetic Studies

1. Personalised Medical Treatment

Due to genetic differences between people a disease can appear slightly differently in different patients. Some of this variability is due to genetic differences between individuals. Personalised medicine refers to the process of analysing a person's genes to identify the type of disease that they have or their response to that disease. This information is then used to create or choose a personalised medicine that is designed to treat the exact form of the disease that they face.

An example of this kind of medicine is Herceptin treatment for breast cancer. Herceptin is a humanised monoclonal antibody that which binds to the HER2/neu receptor that is over-expressed in some breast cancers. If genetic analysis shows that the breast cancer is the type of cancer which over-expresses the HER2/neu receptor, then it can be treated with Herceptin. Herceptin binds to the HER2/neu on the cancer cells and reduces proliferation.

2. Diagnosis of Disease

In some types of disease it is possible to identify the type of disease based on a genetic test, especially in the case of cancers.

For example, if a disease occurs repeatedly within a family and it is suspected that there is a genetic cause for the disease, a number of members of the family might give samples and information about whether they suffer from the disease. These samples could then be compared to one another to locate the genes responsible for the disease, in the hope that this would lead to a treatment for the disease

3. Genetic Epidemiology (Biobanking)

Genetic epidemiology, or as it is more commonly known, biobanking, involves the collection and storage of biological materials, usually human tissue or blood samples. The samples may be accompanied by clinical information from the person who gave the sample. Biobanks may also contain bacterial, plant, animal or environmental samples. The large amount of information stored in biobanks can then be used in research to understand the complex interaction between genes and the environment in the cause of disease.

Biobanks are only currently being formed however it is hoped that they will be used to elucidate the mechanism of disease such as diabetes, heart disease and cancer.

4. Envirogenomic Studies

Some genetic studies are interested in the how the environment interacts with a person's genetic make-up and how these interactions impact the person's health. These studies are known as enviro-genomic studies.

5. Anthropological Studies

Anthropology is the study of humanity and some branches of anthropology use genetics in their work. They look at patterns of genetic similarity among different human populations to elucidate information about such things as, the way human beings evolved, patterns of migration, fluctuations in population

size and the relationships between populations of human beings on different continents.

6. Other Research Studies

There are lots of applications for genetic studies and there will be studies that fall outside the examples given above, especially with the increasing use and application of genetic information in other fields of study.

Process for Undertaking Genetic Studies in the Cook Islands

1. All research which occurs in the Cook Islands must be reviewed and approved by the Cook Islands Research Committee (CIRC), including research that involves genetic studies.
2. The CIRC can consult experts, either domestically or internationally, on a research application.
3. Only once approval of the CIRC has been received may research commence in the Cook Islands.