
Preface

Recent technological advances, primarily in molecular biology and genetics, have greatly improved our ability to investigate how interactions between genes and environment affect our health. Access to reliable information concerning family members, health, and life-style factors that can be linked to biological samples from large numbers of individuals creates an enormous new potential in this area. Although biobanks can be used to study conventional risk markers (such as cholesterol levels and cardiovascular risk), a major emphasis is being placed on the potential for genetic studies. Current studies frequently demonstrate that the importance of genes becomes most evident under circumstances determined by life-style factors. For example, the importance of serum cholesterol for cardiovascular risk can be viewed in a context of genetic variation of lipoprotein genes, receptors, and diet. Modern biobanks are systematically built to allow comprehensive recruitment of cases and matched controls from the same background population and social strata. At the same time, international biobank collaborations allow studies with large number of subjects, where generalizability of findings across populations can be investigated. For such studies, it is of vital importance to establish quality criteria concerning the nature of the sample, conditions of sample storage, and the adequacy of available information. Several collaborative studies and networks are currently actively attempting to develop uniform methods and quality standards – so-called Good Biobanking Practice.

Biobanks that comprise samples stored over a long period of time present the opportunity to investigate accumulated, prospectively occurring disease endpoints – now. New prospective biobanks recruiting participants from a very young age are being designed to contain uniform information and sampling of great future value. Many clinical biobanks consecutively recruit specific clinical cases as they are diagnosed. Current efforts are underway in several countries to produce new well-defined prospective biobanks based on obtaining material from large proportions of the entire population. The visions, organization, and financing of these major efforts differ. Some have received overwhelming popular support, but others are faced by opposition. Biobanking needs to build on public trust, and a high ethical awareness with sound ethical principles governing all use of biobank materials to protect the safety, integrity, and autonomy of sample donors is essential.

We would like this book to contribute to the development of competence in the subject area of biobanking. We discuss how it is possible to use existing collections of biological material to answer significant questions concerning the cause of disease, without violating the personal integrity of participating sample donors. We gain experience from researchers who have succeeded in creating large prospective research biobanks and those who are actively engaged in producing new biobanks. We discuss the ethical issues surrounding biobanks, e.g., the issue of broad consent for the present and future research on biological material. We discuss guidelines for the use of coding systems and the use of biocomputing and registry linkages in research projects. Epidemiological study design is discussed by qualified experts in the field, as is the choice of appropriate technical platforms for different stages of biobank-related research. Finally, several chapters focus on specific clinical topics using biobanks and registries.

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