Report of workshops

1. Science and Medicine
   Chair Dr C. Scerri

Dr C. Scerri presented the problem of controlling the researcher working privately in his laboratory.

Professor A. Xuereb expressed the need for different ethics committees to service the different faculties at the University as well as on a national level.

Ms M. Sant Fournier presented the pharmacy model: research in this field is subject to on-site surveillance as well as peer review. It is difficult to maintain secrecy in research in the case of privately funded research if there is on-site surveillance.

Dr B. Gafa’ said that there exists a law that lays down strict controls on laboratories, but enforcement is lacking. What is required is a culture of ethics that is based on objective criteria. This will not solve the problem but it can contribute towards regulation. The more widespread this culture the better the control.

Professor J. Sandor said that legislation cannot ever control all aspects of research and unscrupulous researchers will always find loopholes in the law. Mutual competitive control can be effective in this sphere.

There was consensus among members present that there should be some form of accountability, and that research should be regulated. It was suggested that scientists be issued with warrants. Moreover there should be regulations and some form of control that these regulations are observed.

2. Science and Pharmacy:
   Chair: Ms M.A. Ciappara

Development of and innovations in pharmaceuticals and pharmacogenetics over the past twenty years have raised the following problems: Is it going to be ethical to stream patients according to
genotype? Is this type of information going to prove a burden to the patient? Should such tests be carried out?

The following comments were made from the floor:

• Tests should be carried out as long as they are beneficial to the patients. No ethical issues are involved since the information resulting from such tests is usually minimal.

• Cost effectiveness and economic feasibility of screening/testing for medicines should be taken into consideration when considering whether such tests are to be held under the national health scheme or privately.

• The public should know as much as possible about availability of tests. On the other hand limited knowledge can be dangerous.

Pharmacogenomics is the study of how an individual’s genetic inheritance affects the body’s response to medicines. It is the application of genetic knowledge to predict the safety, toxicity and/or efficacy of medicines in individual patients.

Hereditary metabolic and molecular disorders and inherited variation in the drug metabolising enzymes, drug targets and drug transporters appear to affect a patient’s response to a treatment. This may lead to increased toxicity to a treatment, risks of adverse effects and ineffectiveness of treatment. The source of these variations appears to be genetic polymorphisms. The identification of single nucleotide polymorphism (SNPs) for drug metabolism and/or drug action can lead to personalised treatment and optimal medicine response.

Testing and screening people for the susceptibility of response to medicines: The ultimate purpose of these investigations is to elicit information that will enable the selection of medicines tailored to individual patients, thereby decreasing the incidence of adverse effects, and improving therapeutic outcome and quality of life of patients. Furthermore, there will be a reduction in unnecessary use of medicines, a more accurate method of determining the appropriate dose of the medicine and better health care. The group discussion focused on the impact of these tests on society, on health care costs, on the individual and on health care professionals.
Impact on society

How aware will patients be to the existence of these tests? Are these investigations justified? Given the availability of these tests, people should become aware of their existence. It was considered unethical not to inform people about the availability of these tests. Eventually, this may lead to widespread testing at an early age to identify genetic variants associated with drug response. The identification and prevention of a toxic response to a treatment justifies the use of these tests. There was no concern among the group that information elicited from the tests was going to be a burden on the patient; however, a dilemma arises when investigations reveal that the current treatment for a condition cannot be used, and that there is no alternative treatment. Treatment has a placebo effect on patient. If no treatment is available the patient may feel abandoned.

Impact on health care costs

Overall how accessible are these tests going to be to everyone? Who is going to fund these treatments? Ideally these tests should be an integral part of the healthcare system. These tests are expensive and can in the short term have a negative economic impact on health care. The group noted that there is going to be a shift from treatment to preventive medicine. While initially the cost is going to increase, in the long term, benefits may balance the cost for the increase in diagnostics and there may be a decrease in the cost of health care. The impact on cost of health care needs to be studied in depth. Economists and health care professionals need to be involved in these assessments.

Impact on the individual

It is envisaged having central databases containing information about patients’ genotypes which can be accessed at the time of treatment selection. This raises the issue of privacy and data protection. Individuals need to have the necessary safeguards placed in the system so that personal details are protected, and there is no misuse of genetic information. Such data can also have implications for insurance policies.

Impact on healthcare professionals

What sort of knowledge do healthcare professionals require? Doctors
and pharmacists need to receive training and education on pharmacogenomics. This includes the interpretation of test results and the selection of treatment on the basis of pharmacogenomics, thereby individualising treatment according to the distinct needs of the individual. The roles of doctors and pharmacists are going to evolve depending on how pharmacogenomics is going to be integrated into healthcare.

3. Science and the Layman
Chair, Ms C. Xuereb

Ms Xuereb stated that in the mind of the general public, the real role of the scientist is vague, and people should be better informed about science and the scientist.

Ways of improving the teaching of science in schools to make it more relevant to everyday life and remove the taboo that it is only a subject for ‘gifted’ pupils were discussed. Hands-on experience is very important - hence the need for school labs and inter-active science centres for the public. The teaching of science in schools should be assigned to specialist and enthusiastic teachers from the earliest years.

There was the need for national campaigns to make pupils aware of, and able to understand more current scientific and ethical problems.