Guide to gender and patient involvement

(within the context of the Value+ project)

Objective:

To assist project partners with the collection of data on gender and PI. Namely to:

- Inform the literature search, the result of which can complement our perception of patient involvement.
- Guide the delivery of interviews and focus groups
- Support the formulation of gender questions for projects with PI only
- Help respondent understand the meaning of such questions
- Support the analysis of gender and PI in the formulation of EC funding programmes

The difference between sex and gender

Evidence from all field of health research show that women and men are different as regards their biology (sex), their access to and control over resources and their decision-making power, and their roles and responsibilities in society (gender). These factors have a great influence on causes, consequences and management of diseases and ill-health. Women and men are biologically vulnerable to certain illnesses in differing degrees and severity and at different times over their life span. Prevention, treatment, rehabilitation and care-delivery need to be adapted largely according to gender. The following are examples of the impact of sex and gender in some disease areas.

Cardiovascular disease

There is a prevailing assumption among public and health professionals that this is primarily a male disease, hence the vast majority of research has been based on studies of men. Cardiovascular disease is the number one killer of women. Women are known to have experience difficulties in obtaining the correct diagnosis and treatment. Life-threatening delays in diagnosis of women may occur because of a lack of awareness of the unique nature of female symptoms.

Autoimmune diseases

Even though men have a higher death rate from autoimmune illnesses such as diabetes and multiple sclerosis, these conditions affect more women than men. But the relapsing intermittent form of multiple sclerosis affects men more severely than women.

Cancer

Some cancers are sex specific (eg. cervix, prostate). Breast cancer is predominantly a female disease. A relatively smaller proportion of men develop it. However, gender also influences the incidence of non-sex specific cancers. Lung cancer prevalence is on average 2-3 times higher in men but declining, the

number of new cases is now particularly associated with smoking in young women (gender impact).

When is it useful to apply gender considerations to patient involvement (PI)?

- When project funding is dependent on either the inclusion or exclusion of gender (or sex) as a variable
  (e.g. women /men's experience of domestic violence)
- When the design of the study needs to be modified to capture differences in male and female responses
  (e.g. differences in the management of emotional well-being, risk taking behaviours, usage of health services)
- When project outcomes are likely to differ according to the gender of end users
  (e.g. lung cancer prevention, CVD rehabilitation)

Some questions to consider when dealing with gender and PI

- Were project leaders aware of the relevance of gender to meaningful patient involvement?
- Were men and women equally involved in the project design?
- Was there equal gender participation among the coordination staff?
- Did the gender mix of patients consulted reflect the nature of project objectives?(e.g. osteoporosis project involving men, CVD involving women)
- Was the project audited for gender considerations in PI? Was there any learning?