

Guidelines for health professionals dealing with vulnerable people

SUMMARY OF ISSUES FOR VULNERABLE GROUPS:

- *There are several factors which can affect a person's competence to either make or communicate autonomous decisions about their medical treatment*
- *Some of these factors might be age (in the case of the very old or very young), where there is a language barrier between patient and clinician, or where a person has a mental or physical impairment of some kind which can affect the clear granting of consent*
- *Patients wishes can sometimes be subordinate to the view of the doctor. Doctors and other health professionals like yourself can move around Europe as it is a free trade area. You should make sure, however, that if you travel abroad to work that you observe the socio-cultural attitudes in the new country in which you practice, rather than those which exist in your own*
- *People in some cultures can be socially bound not to express their wishes or desires. In particular, there are cultures in which women are not permitted to make decisions which may affect the family in certain ways. In these cases, a person can be competent to make a decision but unable to communicate it*
- *Within Europe all individuals are legally entitled to self-determination and to choose freely, regardless of race, gender or socio-cultural status. This is enshrined in the. You may wish to inform your patients of this if you experience cases in which you believe that an individual's view may be being suppressed. The following link will take you to the convention:
<http://conventions.coe.int/treaty/en/Treaties/Html/005.htm>*
- *Certain ethnic and cultural groups will not allow some medical procedures on moral or religious grounds. It is illegal to compel individuals to undergo a procedure, however you should explain the outcomes of any*

decision that they do make in order that they have all the information on which they can base a free choice

INFORMATION ABOUT ISSUES OF RELEVANCE TO VULNERABLE GROUPS

Anybody can be vulnerable if they have a medical condition, particularly one that is serious or debilitating

Some groups however can be especially vulnerable for other reasons, especially when trying to access medical advice for genetic conditions, or when consenting to treatment or research:

Economic status

Mental handicap or mental illness

Age

Ethnicity

Sex

If you have a patient in one or more of these categories, it might be difficult for them to make or communicate decisions to you

They may be unable to make or communicate adequately fully informed decisions about their own treatment and what is best for them, for example when considering undergoing genetic testing or donating biological samples for research

Economic Status

Funding of genetic services is unevenly distributed across Europe at all levels, from the local, to the national and international. This may be the case in the country in which you practice

- If genetic services are sparse where you practice, you may not know where to direct your patients to get the information that they need. There may be a diagnostic test available, or there may be a support group for a condition that your patient has or may have
- You can find out about genetic testing in different European nations by contacting your national genetics network, using this link:

http://www.wordsandpeople.com/eurogenguide/european_societies.htm

- There is a correlation between wealth and health. Economic prosperity tends to correlate with better health because it correlates with better education. Education about diseases and how to diagnose, treat and prevent them requires investment. Investment in health education brings about improvements in health. You should help to educate your patients about genetic disease, why it occurs, how it can be treated and prevented

Mental handicap and mental illness

Somebody who is mentally ill or mentally handicapped may not be competent to make autonomous decisions about their treatment, or they may be able to make decisions but have difficulty with communicating their wishes

[Mental handicap](#)

[Mental illness](#)

Mental Handicap

- Mentally handicaps tend to be conditions that are permanent and chronic. An example of a condition like this is Down syndrome
- People with mental handicaps may be restricted in their competence to make and / or communicate decisions about their medical care, although this can vary a lot between individuals

Mental Illness

- Mental illness, unlike mental handicap, can be temporary, even if the person may have developed the condition because they are genetically susceptible to certain kinds of mental conditions
- Individuals affected by schizophrenia, for example, can have periods when they are more seriously affected by their condition than other times. Their competence to make and communicate autonomous decisions can vary, and there may be times when they are quite capable of doing so, whilst at other times they require care and need others to be responsible for them
- The day-to-day mental health of an individual affected by this type of condition can be affected by a wide range of factors and events in their lives. Some people are genetically more susceptible to the effects of external factors (for example, certain kinds of chemicals found in some drugs) that can cause or worsen the effects of mental illness
- You should bear these factors in mind if you have a patient who has mental difficulties and who might benefit from a diagnostic or predictive test, or who may be able to benefit from participating in research. Just because somebody is mentally ill and may find it difficult to make fully autonomous decisions for themselves at one point in their life, does not mean that they will be unable to do so at all other times

Age

Age may be a factor that can affect someone's competence to make or communicate decisions about their treatment

- In adulthood, in the absence of mental illness or disability, people are competent to make decisions about their lives and their medical care

However, when someone is very old or very young, the stage of mental development which they are at can compromise this competence

Dementia is associated with old age, and it can affect a person's ability to think rationally and act autonomously when making decisions

Similarly, children are often not mature enough to make fully rational choices. Adolescents, whilst nearing adulthood, can also be vulnerable as they may appear to be more competent than they are to make serious decisions about their health

- Decisions about genetic testing can be complex. If you have a patient whose age could compromise their competence to make or communicate a decision, you should explain the patient's treatment options clearly to the patient's carer or whoever is responsible for them.
- In some cases, the carer may need to make a decision on the patient's behalf. In these cases they will need as much clear information as any patient would

Ethnicity and Vulnerability

Nobody is especially vulnerable just by being from a particular ethnic background

90% of the genetic variations that exist in all humans, are found in every ethnic sub-group

However, some variations are more often found in people with family and ancestry from specific areas of the world. This can mean that certain ethnic groups are more susceptible than others to developing particular conditions.

Some ethnic and religious communities object to certain sorts of medical procedure. Decisions like this are personal, but they can make the difference between life and death. You should always inform your patients of the outcomes of their different options so that they are able to freely make a choice.

If you have a patient from an ethnic group that has a high incidence of a particular disease, you should discuss testing with them in order to confirm or eliminate a diagnosis. Three examples of conditions that tend to be more prevalent in specific ethnic groups like this are:

- Thalassaemia - in people of south mediterranean and asian origin:
<http://www.ukts.org/>
- Sickle Cell disease - has a higher incidence in african communities:
<http://www.sicklecellsociety.org/>
- Tay Sachs disease - more often found in people of Jewish heritage:
<http://www.climb.org.uk/>