GMC draft guidance on Decision-Making and Consent
A response from the National Secular Society's Secular Medical Forum

22 January 2019

About

1. The National Secular Society (NSS) NSS is a party-politically neutral organisation that works for the separation of religion and state, and for equal respect for everyone's human rights so that no one is either advantaged or disadvantaged on account of their beliefs. We regard secularism and freedom of expression as essential features of a fair and open society.

2. The Secular Medical Forum (SMF) provides expert and professional advice and opinion on issues related to healthcare. The SMF's main objective is to advocate the value of secularism/religious neutrality as a professional standard in healthcare. The SMF opposes religious influences in healthcare where these adversely affect the manner in which medical practice is performed. It works to protect patients from the harm caused by the imposition of religious values and activities on patients and challenges traditional religious privileges in healthcare service provision or decision-making.

3. We welcome the opportunity to respond to this consultation. We will make some general comments about the guidance and then focus on some specific areas.

General impression

4. The draft GMC guidance on decision making and consent sets out excellent guiding principles for use by doctors when making decisions with patients. We commend the detailed and helpful explanatory notes demonstrating the importance of ensuring that each patient is empowered to make the decision that is right for them having been guided by an appropriate professional with sufficient time, information and expertise. Only in exceptional circumstances can consent by bypassed, such as the need for emergency surgery in the emergency room.

5. We appreciate and support both the general tone and the specific content of the draft guidance. In particular, we wholeheartedly endorse the following sections:

    a) The general statement in the Ethical and Legal Framework that "*Doctors have an ethical and legal responsibility to involve patients as much as possible in making decisions about their own health and care;*

b) The advice in para. 22 that doctors *"must take all reasonable steps to plan for foreseeable changes in a patient's capacity";*

c) The advice in para 41. that doctors "*should not let their own wishes or preferences influence the advice they give and they must not put pressure on a patient to accept their advice.";*

d) The advice in para 63. that doctors should be aware when "*patients may be particularly vulnerable";*

e) The guiding principles in paras. 79, 84 & 85 when considering medical intervention for a patient without capacity. In particular, the advice to doctors to take the action which is "*least restrictive of the patient's rights and freedoms including their future choices… and to consider whether the patient's lack of capacity is likely to be temporary or permanent."*

6. However, we have concerns that the principles in this guidance are subverted and contradicted by other GMC guidance; we discuss this in more detail in our response. We urge the GMC to reconsider the guidance in these other areas to remove the inconsistencies and ensure that all GMC guidance is concordant and maintains as the first concern of every doctor the care of the patient, and not the patient's parents or community. This would ensure that all patients are given the full opportunity to contribute to meaningful decisions about their own health and their own bodies.

Specific concerns

7. Our main concerns relate to two specific scenarios:

   Scenario 1: When a patient is put under pressure either by their family or community or by their doctor to choose a specific treatment

   Scenario 2: When a patient without capacity is given a treatment or intervention that is not medically necessary.

8. Scenario 1 is appropriately addressed in the body of the guidance – i.e. paragraphs 41, 44 & 60-64 which we endorse.

9. Scenario 2: Some cultural practices involve medical interventions or refusal of medical interventions generally considered to be harmful. Examples of such practices are facial scarification, ritual genital cutting, avoidance of blood transfusions and reliance on prayer rather than medication for conditions such as diabetes. We endorse the draft guidance where an adult with capacity is permitted to make a choice about their own healthcare that may be considered unwise or harmful so long as they are not considered under duress to do so.

10. Our concerns relate to vulnerable adults within such communities who may find it very difficult to seek independent medical advice and support to understand the implications of their choice. And we have graver concerns where children and adults without capacity are subjected to or refused medical interventions on the basis of the views of their relatives or community.

11. This is a particular concern when the person subject to this medical intervention or denial of treatment will most likely later gain or regain the capacity to make the decision and when that decision does not need to be made as a matter of urgency. It is not infrequently the case that a child's family will argue that it is in the child's best interests to have a religiously or culturally mandated medical intervention or denial of treatment on the assumption that the child will later adopt the beliefs and practices of their birth community. Yet many children do not later follow their parents' beliefs or practices. However strong the parents' beliefs, no child should be denied the opportunity to form their own beliefs. Just as importantly, all children should be adequately safeguarded from harmful or potentially harmful medical interventions or omissions until they are old enough to choose for themselves.

12. Here are three illustrative examples:

    a. A distressed patient seeking medical advice from their general practitioner who urges the patient to embrace the doctor's own religion.

    b. A child of Jehovah's Witness parents who suffers traumatic blood loss for example and is advised a blood transfusion by the attending medical team but whose parents seek to refuse that treatment on behalf of their child.

    c. A male child born into a Jewish or Muslim family whose family seek a doctor to provide the traditional ritual cutting of his penis which the orthodox variants of these religions still mandate.

13. We will address each of these in turn applying the principles in the draft guidance:

    a. The draft guidance advises doctors not to 'let your own wishes or preferences influence the advice you give and you must not put pressure on a patient to accept your advice.' The draft guidance therefore explicitly covers this scenario. However, some confusion may arise in terms of addressing the perceived 'best interests' of the patient. Some doctors hold a sincere belief that their own religion will provide emotional, physical and spiritual health benefits for their patient. Patients consulting with such doctors may feel pressured and coerced into accepting the doctor's religious recommendation and may not be aware of other options. As an example, in 2012, a Margate GP, Dr Richard Scott was given a formal GMC warning for inappropriately imposing his own personal religious views on a patient.
    We recommend that the draft guidance includes a specific comment about the importance of doctors being able to distinguish between their sincerely held personal, including religious beliefs, and their professional opinion informed by evidence and medical consensus opinion.

b. The situation of a child of Jehovah's Witness parents has come before the courts on several occasions. On each such occasion, the courts have determined that the health needs of the child are paramount and that the religious or cultural views of parents should not be permitted to deny a child necessary treatment. The salient determining factor here is that the choice is not being made by someone with capacity for themselves but by someone else on their behalf. The right to express one's religious beliefs must be limited when it risks causing harm to others as per article 18(3) of the International Covenant on Civil and Political Rights (ICCPR).
Thus it is known that the religious and cultural beliefs of some adults may result in harm or danger to others so there is no rationale for accepting the beliefs of parents *as a priori* in the best interests of their child. Note that article 18(4) of the ICCPR which is sometimes cited as an apparent justification for parental medical interventions for their children, is instead limited to advocating parental rights over the religious education of their children.
We recommend that the guidance makes clear that where a child is unable to give informed consent and thus consent is exercised by a parent or guardian that this consent is valid only as exercised in the best interest of the child, in accordance with the standards of the Children's Act.

c. The ritual cutting of a child's genitals by some communities in the UK and around the world is a common practice. This practice transcends religious, cultural and gender boundaries. It is in this one area that the otherwise excellent draft guidance is most subverted by GMC guidance elsewhere. In particular, this draft guidance is discordant with the guidance contained in the GMC's guidance on 'Personal Beliefs and Medical Practice' paras 18-23.
This is despite legal precedent that ritual male circumcision constitutes 'significant harm' under the terms of the Children Act' (*Re B and G - Sir James Munby's decision) and that the courts have repeatedly ruled in favour of waiting for infant circumcision where there is a disagreement between parents.*
We recommend that this draft guidance explicitly addresses this issue and no longer allows parental beliefs, however strongly held, to be a determining factor in non-essential surgery on babies and children.

14. Further, we recommend that alongside the guidance, the GMC produce case studies and advice specifically addressing a range of such scenarios.

15. It is not sufficient to assert that parents make decisions about their children all the time or that religious beliefs are sincerely and strongly held. We have seen above that some decisions, such as blood transfusions, must be taken out of parents' hands when the end result may be harm to a child.

16. It is not sufficient to assert that certain religions or cultures require a certain practice. The draft guidance goes to commendably detailed lengths to ensure that patients are involved in the decisions that most affect them. In most circumstances it is self-evident that the most vulnerable patients of all, i.e. small children and babies who cannot consent and who cannot defend themselves, are granted even greater protection than adults. In these situations doctors must consider the safeguarding needs of the patient in front of them.

17. Yet, in this one area, GMC guidance on Personal Beliefs and Medical Practice leads one inexorably to the conclusion that the GMC considers it acceptable to rely on parental beliefs as a proxy for a child's future beliefs even though it is known that many adults, whose genitals were forcibly cut as infants to satisfy the beliefs of their parents, are profoundly distressed that this was done to them before they could consent, dissent or resist. Many such adults have suffered physical, sexual, emotional, spiritual and psychological harm as a direct result of the surgical assignation of their parents' beliefs on to their most intimate parts. In this way, the principles and advice in this draft guidance which we support, directly contradict existing GMC guidance.

18. One of the most fundamental rights of all is the right of a person to freedom of thought and belief (Article 9 of the HRA). Whether or not a child will align themselves with the religion or culture of their parents is unknowable when they are a baby. The guiding principle in this draft guidance of maximising patients' opportunities to make decisions for themselves is therefore wholly subverted when doctors collude with parental or community requests for major irreversible surgery on the most intimate parts of a child's body before they can even think for themselves.

19. The draft guidance commendably advises doctors to consider the most vulnerable; it is perverse that the most vulnerable of all are not in fact protected by following current GMC guidance.

20. To avoid confusion, we recommend that the GMC draw a clear distinction between what is acceptable to society and the duties of a doctor which have become confusingly entangled in this area.

21. Firstly, when a patient requests a treatment for themselves which is not medically indicated it is already clear that the doctor has no requirement to provide the treatment e.g. cosmetic surgery. By extension, a doctor should be even more cautious about providing a non-medically indicated intervention or treatment for someone who is incapable of giving informed consent.

22. It may reasonably be argued that the decision as to which cultural practices may constitute safeguarding concerns is one for society to determine and not necessarily for doctors. Practices such as facial scarification, childhood piercings, corporal punishment, forced genital cutting, strictures on teaching about homosexuality or surgical punishments such as amputations or the death penalty are variously permitted or prohibited in different jurisdictions at different times. The medical profession may contribute to these discussions but need not collude in the outcome. For example, the World Medical Association supports United Nations General Assembly Resolution 65/206 calling for a moratorium on the use of the death penalty describing medical participation for example in age determination or prior medical assessment as unethical.

23. Whether society agrees or disagrees with the forced genital cutting of infants and young children, it is the role of doctors to provide good healthcare and to protect the most vulnerable. This draft guidance on consent appears to support this sentiment and practice.

24. **We recommend that GMC guidance explicitly address this matter. If society continues to allow that children's genitals may be cut in the community, there is no rationale for importing that into the medical profession**. Arguments for damage limitation are equally as unacceptable in this area as they are when applied to medical participation in the death penalty, in FGM, or in limb amputations.

25. If ritual male circumcision is to be allowed by society, there is no reason for doctors to be involved. In fact, by following this excellent draft guidance, there is every reason for doctors to challenge societal acceptance of this practice by highlighting the many dangers rather than colluding with it.

Further comments

26. Maximising patient autonomy lies at the heart of good future care planning and alleviating associated stresses on patients. This could be further emphasised in paragraph 53 of the guidance, which we already strongly endorse.

27. We would be happy to provide further information and evidence if that would be helpful. We would welcome the opportunity to meet and discuss this guidance.

Consultation response prepared by:

Dr Antony Lempert MBBS MRCGP DCH DRCOG
Chair, Secular Medical Forum
Healthcare spokesperson, National Secular Society