

Are screening practice ethics committees needed?

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Wald and Neely report in this journal that the UK National Screening Committee (NSC) has set up a sub-committee (the Pilot Ethics Task Group) to review the ethics of child–parent screening for familial hypercholesterolaemia.¹ This is a method of screening that tests children at age 1–2 years at the time of routine immunization. If positive, their parents are tested to identify the affected parent. In this way, two generations are screened together. The NSC suggests that all proposed new screening programmes be subject to ethical review (see ‘Embedding ethics at the UK NSC’ <https://phescreeing.blog.gov.uk/2021/03/23/embedding-ethics-at-the-uk-national-screening-committee/>).

Medical *research* is already subject to ethical committee review but with the exception of fertility treatment this is not the case with medical *practice*. Is there a reason for screening advisory committees such as the NSC to introduce them as a further test in addition to assessing whether a screening method and programme are worthwhile? There are existing criteria for assessing screening tests and programmes which include the requirement that screening programmes are ethical, but this does not mean that separate ethical committee review is necessary or desirable.² The ethics largely arise from assessing screening performance and whether a remedy is available to avoid serious disease or disability, and promptly adopting screening improvements that decrease false-negatives and false-positives. Offering a useless screening test is unethical as is failure to adopt affordable improvements.

Medical screening is voluntary. Individuals can judge for themselves whether they regard a given screening programme as acceptable or ethical; for example some women may reject antenatal screening because the final intervention is an induced abortion. Choice and consent to screening and any intervention that may follow a positive screening result are important ethical safeguards in themselves. It is arguable that ethical review by a public agency, such as Public Health England, in respect of a screening programme deemed to be worthwhile is itself unethical because it may deny people access to a service that many would want and accept; a service that could relieve suffering and the prevention of serious medical disorders.

To even suggest that it may be unethical to have ethical committee oversight may seem strange, but such a requirement replaces individual choice with institutional decision making in areas where individual choice should prevail. It denies autonomy because one cannot choose to have a screening test that is not available. Provided that a screening programme is lawful and is also justified on scientific and medical grounds,

the individual is sovereign in determining the ethical position. The decisions of such a committee could not only deny public access to useful medical advances but also could offend some people by giving ethical endorsements that conflict with their own views. Also, screening programmes need to be supported by research evidence. The research has to have undergone ethical scrutiny, and if the screening process and intervention had been considered unethical at the time, the research would not have been allowed to proceed.

Of course genuine ethical issues must be considered in medical practise, including screening, and should underpin everything that is done by health practitioners. There is, however, a danger that setting up medical practice ethics committees will generate spurious ethical issues that delay the introduction of worthwhile medical advances, and they may even tend to be self-perpetuating regardless of whether the committee is necessary. It is also likely to transfer responsibility for medical practice from practitioner to committee, which would not serve the interests of the public. An example is whether the use of antenatal DNA screening for trisomy 21, 18 and 13 raised new ethical issues, a question considered by the Nuffield Council on Bioethics. The Council decided that it did and proceeded to provide a report with recommendations that were published on 1 March 2017.³ However, quantifying the measurement of nucleic acid fragments in the blood of pregnant women is not ethically different from measuring proteins (such as alpha fetoprotein) or steroids (such as oestriol) or taking fetal ultrasound measurements (such as nuchal translucency). There was no need for the Nuffield Report.

An ethical issue to consider is ‘Equity’, usually implying fair access to a screening service. Equity is a reasonable requirement for a medical screening programme and is one that is beyond the control of an individual. Necessarily some people will not be offered an intervention because they are designated screen-negative even though they could still be affected; for example, people below a screening cut-off, be it based on age alone or an estimate of the risk of the disorder being screened for. Furthermore, some people may not be offered a screening test or procedure; for example, childless couples in child–parent screening for familial hypercholesterolaemia. But withholding a benefit from all because some will not be eligible to receive it would surely be unethical in itself, even though it might appear to adhere to the principle of equity.

There is, however, a better way to judge equity. To use the same child–parent screening example, identifying couples who have had a newborn child 1–2 years ago can be regarded as the

initial screening test or enquiry when offering routine child immunizations. Seen in this way, no-one is excluded from the screening programme; affected childless individuals would be missed and hence be false-negative. Such false-negatives would become less common over time as child-parent screening became established. Another example relates to breast cancer screening. Selecting women of a certain age, say 50 years and over, for a mammogram involves two initial sequential 'tests' or enquiries: first identifying women in a population (breast cancer can affect men, albeit rarely) and then those aged 50 years and over (women under 50 can have breast cancer). This does not mean individuals are 'excluded', as they are part of the screening process. From this perspective all screening is universal; setting so-called 'eligibility criteria' for access to screening is itself screening. What needs to be specified is how people are selected from the population for special investigations such as a blood test or an X-ray, recognizing that these selections are screening steps. What is relevant is whether, within the parameters of an overall population screening protocol, all people are treated alike. This is how screening programmes should be judged in meeting the requirement of equity. As protocols are improved, by increasing detection rates and reducing false-positive rates, the screening parameters will change.

In conclusion, the NSC, which advises on population screening, is adopting an unjustifiably cautious approach to approving affordable innovations, which could result in lost or delayed health benefits. It should be more proactive in supporting screening advances that meet the recognized

requirements of worthwhile screening tests and programmes without imposing an extra tier of ethical committee assessment.

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