

Ruth Butlin shares experience of voluntary work with NHS agencies.



WHEN A CHRISTIAN VOICE CAN BE HEARD

key points

- Service on Regional Ethics Research committees present unique opportunities for Christians to be a gracious influence.
- Committees try to ensure that resources are not wasted and patients are not unduly burdened by onerous tests and procedures.
- No particular qualifications are needed for appointment to a committee: what matters are qualities of character.
- Associate hospital managers have an important role in hearings under the Mental Health Act where vulnerable patients are at risk of being wrongly detained.

As Christians, we have a responsibility to use our God-given abilities for the good of society.^{1,2} This applies not only to 'spiritual gifts' and 'natural talents' (such as musical aptitude), but also to the skills and knowledge we have acquired in the course of our professional lives. There are many opportunities to use our abilities within church-related settings, however to be influential in wider society, some of us Christians must be out in the secular arenas where ethical dilemmas are being addressed. Christian healthcare professionals can use their gifts through voluntary opportunities within the NHS.

Protecting participants in research

Within the NHS a huge amount of medical research is being conducted. Some of it is to fulfil requirements for an educational project (an MSc, a PhD or an MD). Research has potential to produce sound evidence on which good clinical decision-making or policy-making can be predicated. It also has the potential – if not properly regulated – to waste resources, to burden subjects with onerous tests and procedures, to invade people's privacy, or to cause actual harm out of proportion to the likely benefit.

All research conducted within the NHS has to be approved by, and is overseen by, The Health Research Authority (a statutory body). To consider applications for medical research projects numerous

regional Research Ethics Committees, composed of volunteers recruited from the general public, operate under the auspices of the HRA. There has to be a mixture of 'laymen' and 'experts' in each committee, but some of those labelled as lay people (those not medically qualified) bring expertise from their own professional fields, such as pharmacology, psychology or statistics.

No particular qualifications are needed for appointment to a committee: what matters are qualities of character, such as integrity, and the ability conscientiously to study lengthy documents. Necessary training is given (legal requirements and a basic understanding of research methodologies). After that, it is a question of using one's God-given powers of reasoning and insight to identify the ethical issues and weigh them appropriately,³ then articulating one's opinion clearly and concisely. In committee meetings all members contribute, so respectful consideration of others' viewpoints is crucial to finding a consensus.

The ethical issues which frequently arise are matters of balancing *actual* risks and burdens to individual participants against *likely* benefits to society, and the protection of vulnerable people from exploitation by professionals.⁴ When patients are conscious of being dependent on a clinician for their treatment, it can be too easy for the clinician to persuade them to participate in a clinical trial. It can

happen without the patient fully exercising personal responsibility for making an informed decision. Distinguishing between procedures which are part of routine clinical care and those which are being done purely for a research project, can be difficult for patients.

One area which presents problems is the study design: if it is not appropriate (including sample size and selection) then the study cannot be expected to produce useful results and hence is intrinsically unethical. Another area which requires a well-informed (albeit subjective) judgement is the level of remuneration offered to participants: it should not tempt one to consent against other considerations.

A Christian voice in Research Ethics Committees is an important contribution to maintaining godly standards for the rights and dignity of individuals who – by reason of their illness or disability – are in a vulnerable situation when requested to participate in a research study.² The necessity for independent ethical review prior to conducting research means that scientists and health professionals safely carry out their studies without infringing the rights of people seeking treatment in the context of a national health service. As a Christian speaking in a committee meeting, it is not so much a question of proclaiming one's faith: it is being guided by the Holy Spirit to make a right assessment of an application and to discuss it graciously with fellow members.⁵

Protecting patients detained under the Mental Health Act

The ability to assess written arguments and to judge the merits of a case is also required for another type of voluntary work in the NHS, the implementation of the Mental Health Act (2007). This Act allows – in specified circumstances – people who are not criminals to be detained against their will in a particular place (and to be administered medical treatment without their consent). This power in the hands of professionals could be misused through carelessness or misunderstanding or, conceivably, by malicious intent or for ulterior motives.

Any person compulsorily detained under the Mental Health Act has legal rights of appeal and of independent review of his/her detention when it is extended. A next of kin also has limited rights to discharge a patient from detention. Those with serious mental illness are often unable coherently to defend themselves. To ensure they do not suffer injustice, independent people are appointed to undertake hearings for appeals or to review extensions. These people are commonly called 'Associate Hospital Managers,' since they fulfil the role given in law to managers of hospitals where the patients are detained. They also have the responsibility of ensuring that the professionals' power of detention under the Mental Health Act is used only in a legal and humane manner. In some places they are called Associate Mental Health Act Managers.

Since the small number of people who are so seriously ill as to need detention are often so

socially-marginalised as to be largely invisible to the general public, their sufferings (or their disappearance into a psychiatric hospital) may go unnoticed. They may have no friend to speak up for them. Defending vulnerable people and the rights of the weak is a Christian duty:⁶ it is a privilege to exercise this duty as an Associate Hospital Manager in the context of the Mental Health Act.

As a Christian in this role, one has to weigh evidence carefully and make a formal decision; all this is done prayerfully as one quietly seeks the Spirit's guidance.⁷ Going home after a hearing, one might continue to pray for the patient. Through prayer, I believe we may introduce something extra, something of God's gracious healing love, into the patient's tragic life.

Patients detained under the Mental Health Act are entitled to speak for themselves, but often are unable to do so. The law provides access to an 'Independent Mental Health Advocate' (IMHA), who helps them to understand their rights and to present their point of view. Some IMHAs are employed by charities for this function, while others are volunteers. This is another role which could be taken on by a concerned Christian.⁸

It is unusual for Associate Hospital Managers to find any professional has wrongfully used his/her power of detention. When the Act is used carefully it is because of the precautions which are in place, such as the power of Associate Hospital Managers to discharge a patient from detention if they find that the criteria are not fulfilled. We must be thankful UK law, based as it is on Christian principles, contains such provisions to protect the vulnerable.

Protecting Christian values in NHS trusts

Though our National Health Service may appear to be run by professional administrators according to policies determined by politicians, wherever there is a foundation trust the public can influence some aspects of the decision-making. Anyone can become a member of a foundation trust, and can then speak and vote at meetings. For greater influence, one may stand for election as a governor (an honorary post).

It must be a good thing to have such positions held by Christians with experience in healthcare (such as CMF members). It is one way we can fulfil our duty to contribute as educated citizens of a worldly democracy, to good administration of the National Health Service. As Spirit-filled citizens of the kingdom of God, we can extend his kingdom into the far reaches of the NHS.⁹ There are many avenues for Christians with some free time to undertake voluntary work of an intellectually-satisfying and often personally-challenging nature. Their Spirit-led contribution will help to preserve the highest ethical standards. One might see it as a way of 'being salt' in the world.¹⁰

Ruth Butlin is a retired medical missionary who worked with Leprosy Mission International



A Christian voice in the research ethics committees is an important contribution to maintaining godly standards

references

- 1 Peter 4:10
- Acts 20:35
- Colossians 3:23
- Leviticus 25:17
- Colossians 4:6
- Psalms 82:3
- Exodus 23:6
- Isaiah 1:17
- James 1:27
- Matthew 5:13