

**PUBLIC CONSULTATION / HUMAN BIOLOGICAL
MATERIAL**

SUBMISSION FROM

MOTHER AND CHILD CAMPAIGN



LIFE INSTITUTE



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PREFACE

In introducing this brief submission to the Irish Council for Bioethics we would wish firstly to state that we make no pretence that it is an exhaustive legal or medical study of the issues involved. The Council has available to it all the relevant information required without recourse to the public submission process and as such it is our view that there is nothing further can be added.

The Life Institute, has a record of involvement in what may loosely be termed the "Life Issue", and while the political context has been to focus our attention and activities, in particular, on the consequences of the X case judgement, you will understand immediately that the questions before the Council have a direct impact on areas of our fundamental concern, although for the purposes of this submission we shall address the wider implications of the questions asked.

We have entered in an age of almost unbridled biotechnical expansion. Almost daily we hear and read media reports recounting advances in medical science which pave the way for human cloning; predetermination of the sex of children and their genetic make up; genetically derived therapies for the prevention and cure of illness and using animals to grow replacement organs for transplant into humans. There is no doubt that human kind may reap great benefits from various biotechnological advances. However, it is also true that unchecked scientific advancement, that is unaware of or indeed hostile to, the ethical concerns, which it poses, may lead to human tragedy and loss of human dignity.

One only has to look at lessons from history; particularly the horrific experiments perpetrated on human subjects by Nazi scientists, to see that this possible.

WHAT IS BIOETHICS?

The most basic definition of Bioethics is that it is the study of moral issues in what can broadly be termed the “life sciences”. It is a subfield of the discipline of Ethics, which is in turn a branch of philosophy.

As an ethical theory bioethics is not “neutral”. It takes a stand on what is right or wrong. We at the Life Institute would like to impress this fact upon the Council and of the enormous weight of responsibility this places on it. More specifically bioethics is an academic ethical theory that was made up in 1979 in the US by an eleven member national commission, which in turn was established in 1974 when Congress passed the National Research Act.

This event in turn, was preceded by several years where congress were called to address an increasing number of problems generated by medical research and the use of human subjects.

In 1979 the Commission issued its final report entitled the Belmont Report. This report identified three ethical principles; respect for persons (autonomy), justice and beneficence. However, almost thirty years on even the founders of Bioethics theory has admitted that bioethics is dysfunctional. For example, Daniel Callahan, one of the founders of the Bioethics think – tank, The Hastings Centre, and former director of the American Eugenics Society has conceded in the 25th anniversary of the Hastings Centre Report, that the principles of Bioethics simply had not worked.

An example of how the so called Belmont Principles can be used to the point of abuse, one only has to look at a piece of legislation drafted in the state of Maryland as recently as 1999, concerning the use of “decisionally incapacitated” human subjects in medical research. This proposed statute purports to “respect the autonomy” of mentally ill human subjects to such an extreme that it would allow them to give informed consent to choose “research agents” who would then “substitutes their judgements” as to whether or not these mentally ill persons would have wanted to participate in even high risk, no direct benefit medical research for “the greater good of society”, were they competent.

We at the Life Institute would forcefully request that the Council would not confine itself to such potentially dangerous principles, when dealing with the serious issues before it.

ISSUES.**On the issue of using stored biological materials, the Life Institute, recommend the following;**

It is not appropriate to use stored biological materials that are coded in such a way that identify the person from whom the material came in ways that were originally not contemplated. In all future routine medical care it must be stated explicitly, that the material obtained may be used for research purposes, in order to allow the person an opportunity to refuse.

We state absolutely that foetal tissue should never be used, as biological material as the person involved, i.e. the unborn child, does not give consent. To do so would be grossly immoral and would undermine his/her dignity as a human being.

On the issue of the person having commercial claim to his or her biological material the Life Institute would ask the Council to consider the following;

Firstly, it is an empirical fact stated by all human embryologists that human life begins at fertilisation and as such the person exists from this point. Any other definition of personhood is merely a philosophical point of view, held by various people for various reasons. Secondly, the issue of whether a person has any legal hold or commercial claim over his/her biological material comes down to whether or not that the person gave up all his or her rights over the material when it was donated. For example does the material become the sole property of the scientist upon donation?

On the issue of ability to give consent the Life Institute believes the following;

That under no circumstances whatsoever should material from people who are unable to give consent be used for medical research. To do so could lead to widespread abuse of the following vulnerable people; the unborn, the mentally ill, people with learning disabilities, the elderly and people in PVS – permanent vegetative state.

On the issue of material already collected the Life Institute proposes the following;

Under no circumstance should material that has already been collected and for which consent has not obtained, be used for medical research.

On the issue of confidentiality the Life Institute believes the following;

To reiterate what we have said previously, all biological material should be taken from people who have consented to it and should be made aware that confidentiality may not be guaranteed. We believe that for people who nobly donate their biological material for the advancement of medical science, confidentiality should not be an issue.

On the issue of the establishment of Biobanks, the Life Institute can envisage a situation where, medical science permitting, people can donate biological material for the purposes of that material being used to aid them in the future. For example science currently envisages a future scenario where a person's own stem cells can be stored, and then used, to develop another organ. We totally reject, however, Biobanks being established for the purposes of growing or storing human embryos for any reason whatsoever.

CONCLUSION.

The Life Institute asks the Irish Council for Bioethics to adhere to the long and noble practise of medical ethics in Ireland, which protect human life at all stages. We urge you to, in writing guidelines, or addressing ethical issues to consider first the dignity of the human person donating any biological material and to reject the unethical practice of using any material without the consent of the donor, especially where said donor is unable to give consent, by virtue of immaturity, age or intellectual inability. We draw your attention to the repeated rejection of abortion and embryo research by the Irish people and the Irish medical profession.

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