

# COMMISSION OF THE EUROPEAN COMMUNITIES

COM(80) 555 final

Brussels, 3 October 1980

Proposal for a  
COUNCIL DECISION

amending Decision 78/167/EEC adopting a concerted  
project of the European Economic Community in the  
field of registration of congenital abnormalities  
(medical and public health research)

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(presented to the Council by the Commission)

COM(80) 555 final



COMMISSION COMMUNICATION TO THE COUNCIL

Proposal to extend the duration of the concerted project (1978-1980) for the EEC in the field of registration of congenital abnormalities (medical and public health research) to four years without increasing the upper limit of expenditure commitment.

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On 13 February 1978 the Council adopted a concerted project for the European Economic Community in the field of registration of congenital abnormalities (medical and public health research). The concerted project - which runs for three years from 1 January 1978 and has an upper limit of expenditure commitment of 330,000 EUA - is due to end on 31 December 1980 (OJ No L 52, 23.2.1980, p. 20).

Under this Decision, the Member States intend, as part of the rules and procedures applicable to their national programmes, to carry out the research work (as described in Annex I of the Decision) and are prepared to integrate that relevant research work which forms part of their national programmes into a process of coordination at Community level, whereas the Commission is responsible for the coordination.

The coordination applies to designated regional registers of the Member States as well as to their registration procedures.

Following the above-mentioned Decision, a Concerted Action Committee (COMAC) was established in conformity with Article 4. The first COMAC meeting took place on 25 May 1978 allowing to draw up suitable rules of procedure, to agree on the project leader to be appointed by the Commission, and to elaborate a feasible working plan.

The subsequent effective starting phase was delayed :

- by the late availability of appropriations to finance the Community contribution to the coordination which made impossible the setting up of a centralized registry in 1978, and
- by some administrative problems at national level.

Consequently, no substantial expenditure were made during 1978, and proper programme implementation could not begin before 1979.

The progress achieved hitherto was mainly conditioned and characterized by the gradually increasing participation of regional registers in this concerted project. Greece and Switzerland are just starting to cooperate within the COST framework.

Therefore, an optimal coordination of the participating national registers, by using harmonized registration methods in common, will not be achieved before the end of 1981.

Continuation together with simultaneous expansion of the regions covered and continuous extension to further congenital abnormalities will be taken care of within the frame of the third medical research programme proposal of the EEC which is presently being drafted.

Therefore, the Commission requests the Council to adopt a decision extending the current concerted project by one year

- without increasing the upper limit of expenditure commitment;
- adapting and completing the list of participating registers mentioned in the Annex to the Council Decision, in particular by the inclusion of a Greek register.

PROPOSAL FOR A COUNCIL DECISION AMENDING DECISION 78/167/EEC ADOPTING A  
CONCERTED PROJECT OF THE EUROPEAN ECONOMIC COMMUNITY IN THE FIELD OF  
REGISTRATION OF CONGENITAL ABNORMALITIES (MEDICAL AND PUBLIC HEALTH  
RESEARCH)

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THE COUNCIL OF THE EUROPEAN COMMUNITIES,

Having regard to the Treaty establishing the European Economic Community,  
and in particular Article 235 thereof,

Having regard to the proposal from the Commission,

Having regard to the opinion of the European Parliament,

Whereas by Decision 78/167/EEC<sup>1</sup> the Council adopted  
a concerted project of the European Economic Community in the field of  
registration of congenital abnormalities (medical and public health  
research);

Whereas, in view of the current stage reached in the work provided for  
under the concerted project, an extension of the project by one year  
would enable the best advantage to be obtained from the national efforts  
being made; whereas Decision 78/167/EEC should therefore  
be amended;

Whereas the Scientific and Technical Research Committee (CREST) has given  
its opinion on the proposal from the Commission;

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(1) OJ N. L 52, 23.2.1978, p. 20.

HAS DECIDED AS FOLLOWS :

Sole Article

Decision 78/167/EEC is hereby amended as follows:

1. Article 1 is replaced by the following:

"Article 1

The Community shall implement for a period of four years a concerted project in the field of registration of congenital abnormalities, hereinafter referred as "the project".

The project shall consist in coordination at Community level of the research described in Annex I, which forms part of the research programmes of the Member States."

2. Annex I is replaced by the Annex to this Decision.

Done at

For the Council

The President

ANNEX

"ANNEX I

RESEARCH PROGRAMME RELATING TO THE REGISTRATION OF CONGENITAL  
ABNORMALITIES

(Concerted project)

The research will be carried out with the purpose of acquiring scientific and technical knowledge in this field, selected for its importance at Community level.

The research is expected to cover the following topics :

1. Registration of congenital malformations as well as of inherited biochemical and chromosome abnormalities in selected regions of the Community.
2. Registration of twins and multiple pregnancies in selected regions of the Community.
3. Relevant methodological studies in order to obtain an optimal co-ordination of both existing national registers and registration procedures.

The coordination will include the following regional registers of the Member States :

Belgium	:	Brugge and Hainaut.
Denmark	:	Odense.
France	:	Paris and Morlaix.
Germany	:	West-Berlin and Hessen.
Greece	:	Euboia.
Ireland	:	Dublin and Galway.
Italy	:	Toscana, Roma and Emilia-Romagna.
Luxemburg	:	Luxemburg.
Netherlands	:	Groningen.
United Kingdom	:	Belfast, Glasgow and Liverpool.

These countries will contribute research under the three topics mentioned above."

