Public health: Community action programme 1999-2003 concerning rare diseases

1997/0146(COD) - 30/04/1998 - Council position

In its common position on the programme of Community action on rare diseases, the Council extensively restructured the Commission proposal and condensed the presentation of the actions. More specifically, the Council rendered more succinct the description of the actions in the annex to the programme, concentrating on cross-border activities and those offering most Community added value. The Council particularly stressed the establishment of a European information network using existing databases rather than setting up a new one. It deleted support for the setting up and strengthening of information networks at local, regional and national level. The organisation of meetings of those working in the field ('consensus meetings') has been replaced with 'recommendations' to improve early detection, identification and prevention of the diseases concerned. The actions relating to patients' groups and their families are rationalised and concentrated on cross-border aspects. The actions concerning clusters of rare diseases are more general and stress Community monitoring of these diseases and early warning systems. Besides general rationalisation of the actions to be undertaken under the programme, the Council also modified other specific aspects of the programme: -commitology: the Council favours the mixed committee procedure over the advisory committee procedure, -budgetary aspects: the Council allocates ECU 6.5 m for the duration of the programme (5 years), -monitoring and evaluation of the programme: the Council considers that the interim report to be submitted by the Commission should also take account of developments which may occur in connection with Community action in the field of public health. The Council incorporated only 6 of the 28 amendments adopted by Parliament at first reading (the Commission had accepted 16 of them). The only amendments accepted by the Council concerned: -the considerable prevalence of these diseases and the fact that they affect a significant percentage of the population, -the serious difficulties they cause to sufferers, -the fact that the treatment of these diseases should be integrated into an overall policy which also relates to orphan drugs and research, -improving, by means of the programme, the knowledge of health professionals, researchers and people directly or indirectly affected by the diseases, -the widest possible public dissemination of information about the diseases. Among the most important of Parliament's amendments which were not accepted by the Council were those concerning the budget (Parliament had called for ECU 14 m), commitology and the establishment of a monitoring and surveillance system making it possible to respond rapidly and effectively to outbreaks of the diseases (establishment of networks and courses relating to their treatment).