

DO YOU WANT TO USE THE REGISTER?

It is hoped that the registry will serve as a base for research and thus contribute to increased knowledge, which should eventually provide even practical use. At the same time, it is important that the people who are on the register not perceive their privacy or autonomy violated. Those considering applying for use of registry information are welcome to contact any of the members of the steering committee or the consulting administration.

- *Applicants and/or co-applicants* should be related in some way to the reporting unit/s.
- *The project* must be approved by the research ethics committees concerned, and where applicable also Datainspektionen, since the authorization already available is only for the "base register". The application must specify the information that is requested and the intended purpose for the information.
- *The application* is sent to the registry steering group who can provide access to the register, however, as always the Pediatric Doctors Association's (Barnläkarföreningen/BLF) child section of gastroenterology and nutrition is informed through its Board of Directors. If the steering committee is hesitant the application is submitted to the board of Gastro Section, and from there possibly to the Board of BLF. Rejection is given only after the application has been processed by both the Gastroenterology Section's Board and the BLF's board of directors. Applicants are always informed in writing of the decision and a justification is given.
- *If a project will involve the children/parents being contacted*, information must be sent in advance to the contact person at the corresponding clinic who reported the child/children. Inquiry to the family should be initiated from the steering committee and the research team together, then contact can be established directly.
- *Access* is provided only to the data specified in the granted application. Information may only be used for the purpose it was sought for and granted, then it shall be erased provided the Data Inspection Board has not decided otherwise.
- *The funding* for so-called basic costs (eg administration time, forms, and postage) will ideally be arranged through the applications emanating from the Department of Epidemiology and Global Health, Umeå University. Should this not be the case, the basic costs are to be divided between those whose research utilizes the registry. The possible extra costs are to be financed through the particular project responsible.