

**For valid and efficient public health monitoring and research, it is sometimes necessary to use personal health data. Modern ICT technologies can ensure sufficient safeguards for personal health data.**

### **PERSONAL HEALTH DATA**

Personal data means any information relating to an identified or identifiable natural person. The use of such personal data is necessary for adequate and efficient public health monitoring and research. Data protection legislation determines to what extent it is possible to use personal health data for different purposes, including public health. Modern ICT (information and communication technologies) allow for high quality health information systems enabling linkages between data sources, whilst ensuring sufficient safeguards for personal data protection rights. The Scandinavian register-based health information systems are good practice examples in this regard.

### **THE LEGAL FRAMEWORK**

European data protection legislation determines the extent to which personal health data can be used for public health purposes. At the core of this is EU Directive 95/46/EC (Data Protection Directive), which serves as the basis for the national Data Protection Acts of all EU Member States. Its objective is to secure the free flow of personal data within the internal market while ensuring a high level of data protection. Due to their sensitive nature, the processing of health and other sensitive data is in general prohibited (Article 8). There are circumstances where public interest can be regarded as overriding the privacy interests of the individual. For this reason some exemptions to the general prohibition to process personal sensitive data are provided in the Directive.

### **PUBLIC HEALTH IN THE DATA PROTECTION DIRECTIVE**

The Directive itself does not directly acknowledge public health as a ground for allowing the processing of personal health data, but it does leave open the possibility for Member States to develop additional national legislation that allows for this. Not all Member States have used this possibility, which has resulted in diverging situations in the countries. The Directive is currently (early 2012) being revised. For the Public Health community it is important to advocate the safe use of (routinely collected) personal health data for public health purposes under this revised Directive.

**European data protection legislation determines the extent to which personal health data can be used for public health purposes. Current practice differs between European countries.**

## WHY DOES PUBLIC HEALTH NEED PERSONAL HEALTH DATA?

The inability to link data sources and to use existing health data to the fullest extent seriously hampers public health monitoring at all levels, jeopardizing data validity and outcome usability, and results in inefficient use of public resources. More specifically the goals of using personal health data for public health are;

- Detailed analysis of health services provided to specific categories of individuals will **optimise the efficiency of health services**;
- Systematic assessment of processes and outcomes across different categories of users in the intermediate and long term will **monitor appropriateness, safety and quality of care**;
- The analysis of deprived groups that otherwise would have been difficult to track in relation to specific interventions will **target equity**;
- The intelligent use of the information available in large administrative databases will **ensure the sustainability of systems of health indicators**;
- The identification of ways to extend the secondary use of health data will **enhance data completeness for evidence-based policy making**;
- Linking of different databases at the subject level will **enhance data quality** and prevent that events are missed or double counted; and
- Increased ability in using health data and the routine performance assessment of health services and systems to support research and development for innovation will **enhance the competitiveness of the European Union**

(Carinci F, Di Iorio CT, Ricciardi W, Klazinga N, Verschuuren M. Revision of the European Data Protection Directive: opportunity or threat for public health monitoring? *Eur J Public Health*. 2011 Dec;21(6):684-5. Epub 2011 Jul 23. PubMed PMID: 21785116) (Stenbeck M, Allebeck P. Do the planned changes to European data protection threaten or facilitate important health research? *Eur J Public Health*. 2011 doi:10.1093/eurpub/ckr160.)



The public should be aware of the benefits of public health monitoring activities. Seeing the benefits of the use of their data will strengthen citizens' confidence in good governance. Having transparent rules for data processing, including rules for accountability, will also strengthen confidence in good governance.

Best practice examples, including privacy enhancing technologies, should be developed, supporting implementation of high quality health information systems that provide sufficient safeguards for individuals' data protection rights. Part of this should be European guidelines on minimum levels of personal data protection.

**EUPHA** should continue to contribute to the safe and efficient use of personal health data for public health through e.g. supporting the development of best practice examples and guidelines, and raising awareness.

The right to protection of personal data is established by European Charter of Human Rights (Article 8), as is the right to a high level of human health care (Article 35). There is a public interest in using existing data sources as efficiently as possible. These different interests should and can be balanced in data protection legislation.

Awareness of and knowledge on data protection issues should be promoted and improved among public health practitioners, experts and researchers. They should be well informed to ensure their work is being carried out in line with existing laws and regulations, and to enable them to improve their quality standards.