EPAAC OPEN FORUM
LJUBLJANA

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Steering Committee Luxembourg
No effective cancer registry operates with informed consent

- West Germany – informed consent, 1990
- Incremental use of consent (code P12)
- Baseline and follow-up responses through 2 years
- Present/past international comparisons
- Increased research output
- East Germany – informed consent, 1999
- Closure of largest European cancer registry (1995)
- Hungary – Personal Data Protection Act 1998
- Cancer registration stopped until 1999
- Nordic countries – statutory, no consent
- Efficient, complete, productive cancer registries
• Improve availability and access to cancer care and services
• Provide a platform for sustainable health planning, education, and training, enhancing social development (LMIC)
• Control adverse aspects of the earlier diagnosis of cancer may bring to QoL, maintain balance

> Governing framework
  - Implement cancer screening programmes
  - Maintain appropriate quality of screening programmes
  - Reach appropriate decisions on new or modified programmes

> Based on:
  - WHO principles of cancer screening (Wilson and Jungner)
  - Experience in implementing cancer screening programmes in EU Member States
http://www.epaac.eu/open-forum/open-forum-slovenia
Thank you!