The way forward

RARECARENet

Proposal for the coming weeks

- Complete the list of issues
- Mail around and ask for comments

- Final list of main issues per tumour type

And then….

- Translation of the main issues into indicators

- Indicator set send for comments

- Per indicator:

  - Name of the indicator

  - Type of indicator (structure, process or outcome)

  - Definition of the indicator

    - Possible nominator and denominator

  - Availability of data in cancer registrations (high volume analysis and high resolution study)

Specific criteria/indicators plan of action

- Check availablility in EU Cancer Registries (CR)

- Some CR will be invited to collect information from clinical files in retrospect (time period important for ability to find data (electronically), partly overlap of period of Wp4)

- Develop a protocol to retrieve data for these High Resolution Studies

High Resolution Studies

- Collect data on specific indicators by high resolution study using a set protocol

- Selected number of CR (partners NL, Finland, Italy, Ireland, Bulgaria, Slovenia, Belguim, Navarra i.e. based on EUROCHIP survey on availablity stage etc)

- Analyse data

- Discuss results with experts

- Describe an advice upon CoE for the specific rare cancers

Timeline

- M9: Send out protocol for data on indicators

- M9-M17:   Collect data from CR (Wp4)

- M17-M19: Data analyses

- M21: Data collection and data analyses completed

- M23: Meeting to discuss output with CR

- M24: Meeting present results to experts > Spring 2014

Expected results and output

- Final Deliverable (No.7):
  - Report identifying criteria indicating the level/quality of expertise for rare cancers management

  → This report will lead to recommendation that can be used for selecting centres of expertise throughout Europe