







Review the Plans/Strategies for Rare Diseases in Europe

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The review process

PRE-REVIEW

- 1. Preliminaries
- 2. Defined important terms
- 3. Read some of the P/S for the first time
- 4. Defined items to be collected
- 5. Elaborated schemes for data collection

The review process

REVIEW

- 1. Documents screening
- 2. Languages used in documents
- 3. Exclude some documents in National lang.
- 4. Exclude documents not considered P/S
- 5. Elaborated schemes for data collection
- 6. Reviewed included documents
- 7. Collect and analyse data
- 8. Data presentation

Clarifications & Assumptions



Planning

Is a process of establishing objectives and determining the best way to reach them.



Planning

- Planning is deciding in advance what to do, how to do it, when to do it and who is to do it.
- It bridges the gap from where we are to where we want to go..



Planning

- > Entails a choice/s
- > It forecasts of a number of actions
- ➤ Will influence the future



Why planning?

Because ...

- There problems and unmet needs
- Problems are complex
- Needs are infinite







At the same time ...

Resources are always limited.



Therefore...

It is necessary to optimise the scarce resources to answer to priority needs.



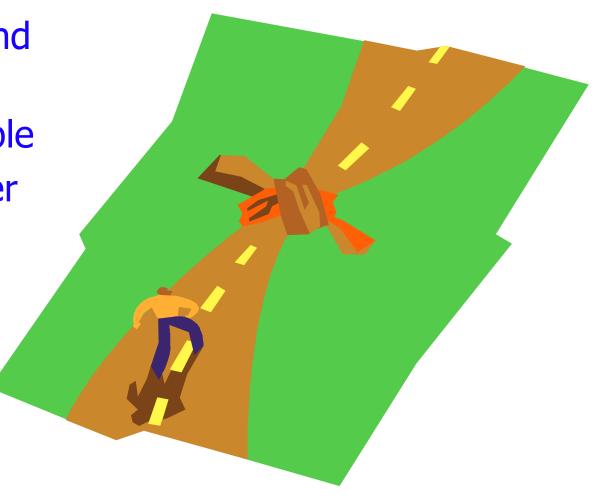
Purpose of planning

- Planning provides direction
- Reduces uncertainty
- Minimises wastes and redundancies
- Sets the standards for controlling



In order to ...

Decide beforehand where to go and should be able to determine later if the destination was reached.



What is a plan?

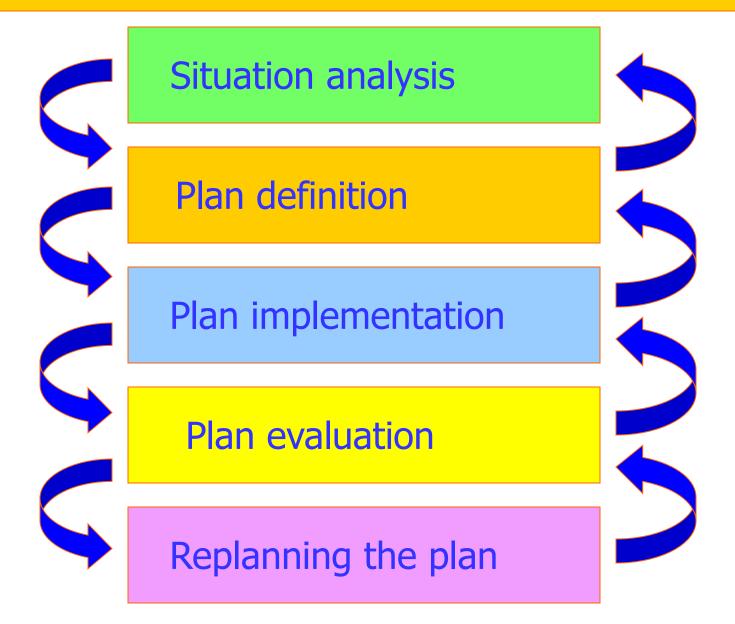
- A plan is a written account of the intended future course of action aimed at achieving specific goals or objectives within a specified timeframe.
- A plan explains in detail what needs to be done, when, how and by whom.



The planning process



The main steps



Situation analysis



Situation analysis

An activity that explore the situation in a specific moment and identifies the problems to be faced.



The main steps of the situation analysis



- Identification of existing problems
- Study the prognostic evolution of the problem
- Study the problems' interconnections
- Determine the priority needs

Planning the plan



The plan

It is a number of <u>activities</u>, <u>strategies</u> and <u>resources</u> spelled out in a document with the aim of reaching one or more <u>objectives</u>.

The plan includes an evaluation system to verify the objectives have been met.



Objectives



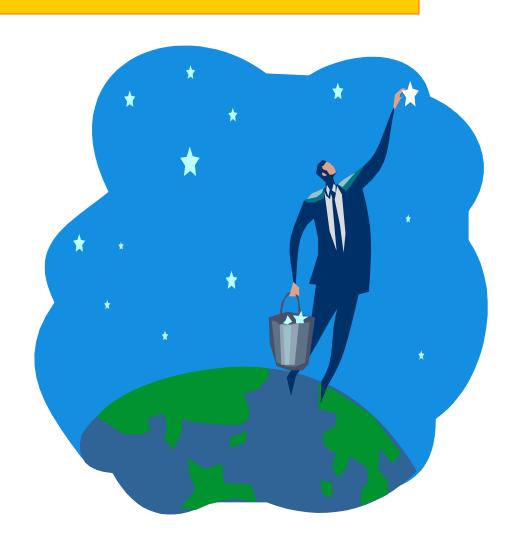
The objective is...

... a
destination
that one
wants to
reach...



Types of objectives

- ➤ Scope
- **≻**Goal
- ➤ General objectives
- > Specific objectives



The scope is...

... a very broad objective.



Scope

"...Health for all by the year 2000."



Goals

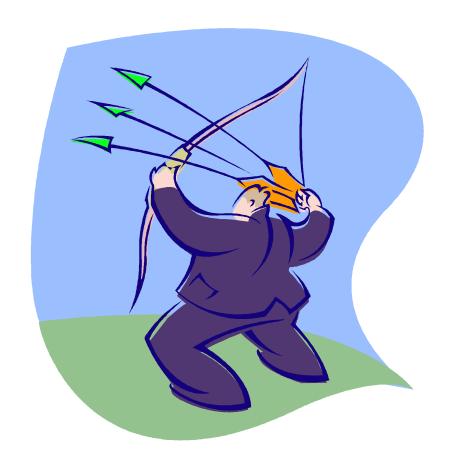
Goals:

- are general statements about a desired outcomes;
- are the end results to be achieved;
- give direction to activities.



A general objective is...

... a declaration that identifies the global aspects that one wants to reach. It may not be measurable.



Specific objective

SO define in precise terms what is to be accomplished within a designated time frame.

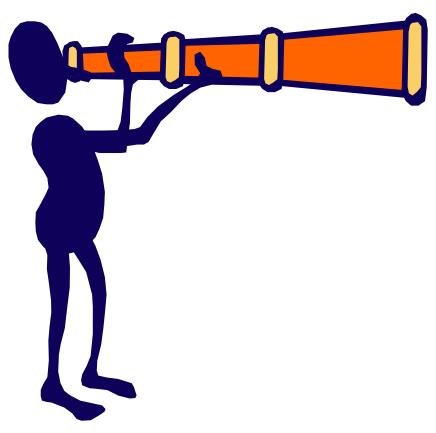
- S Specific
- **M** Measurable
- A Attainable
- R Realistic
- **T** Timely



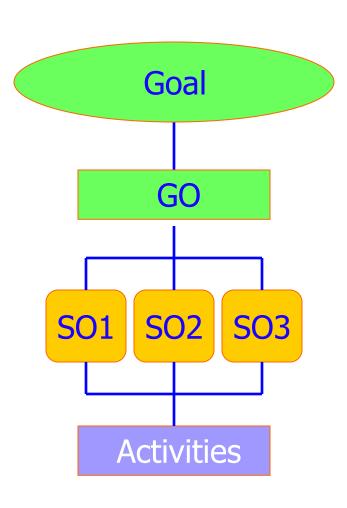
Measurability of SO

The SO must answer to these questions:

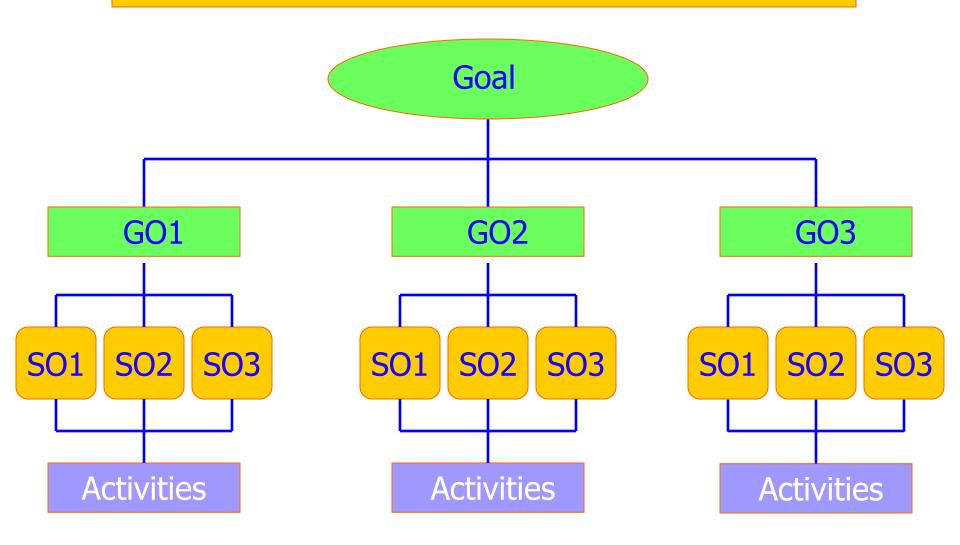
- What?
- How much?
- When?
- > Who?
- Where?



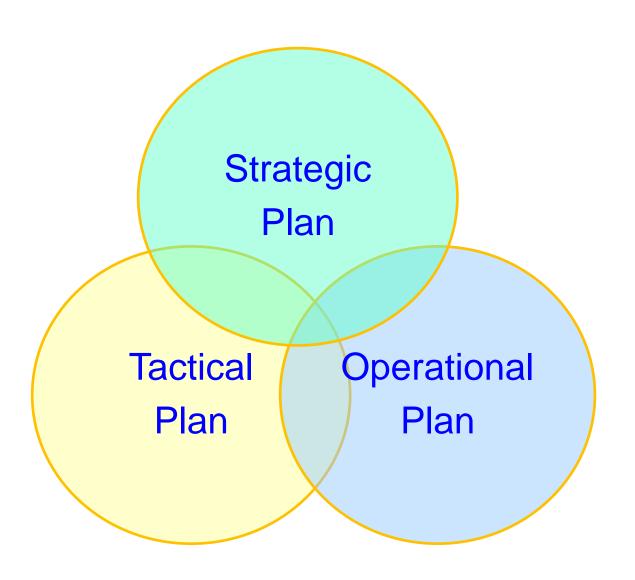
Hierarchy of objectives



Hierarchy of Objectives



Types of plans



Strategic Plan

Strategic plans define the broad goals and the strategy formulation process.

Operational plans contain details for carrying out, or implementing, those strategic plans in

day to day activities.

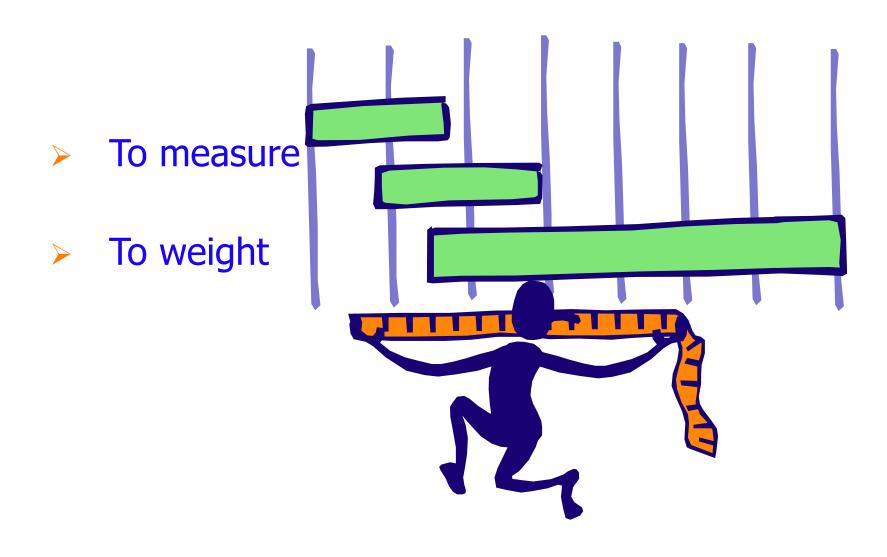


The plan of action

- Activity: what
- Resources: with what means
- >Time: when
- Place: where
- Strategy: how
- Budget: how much
- Foreseeable risks
- Evaluation plan



Evaluation



Types of evaluation

- **≻**Monitoring
- Supervision
- > Evaluations:
 - process
 - result
 - impact

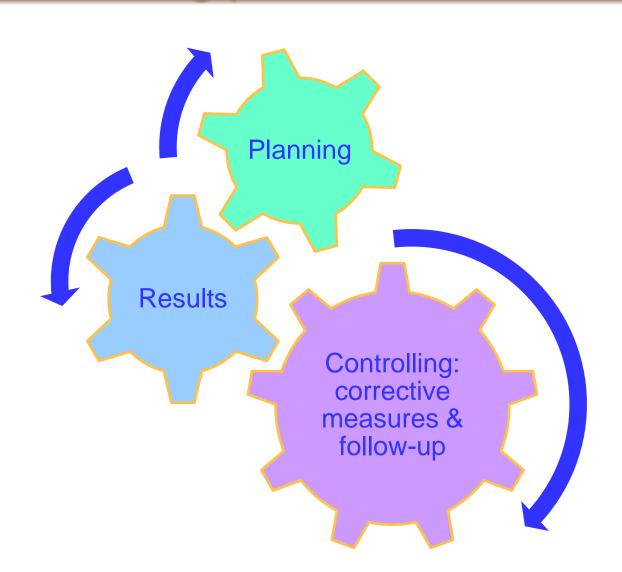


The indicator is...

... a value, foreseen in a particular time to capture the progression of a change.



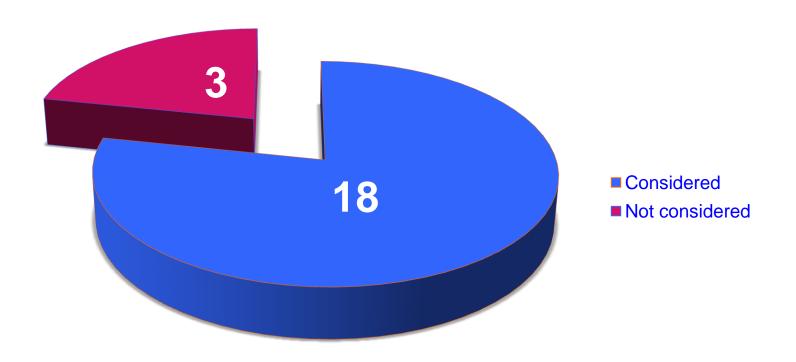
Panning and Controlling... an unending phenomenon



Main Findings



Total entries for review = 21

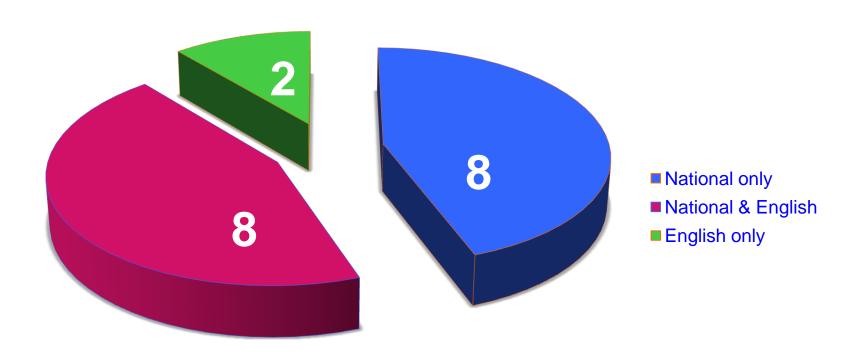


Reasons for exclusion from review

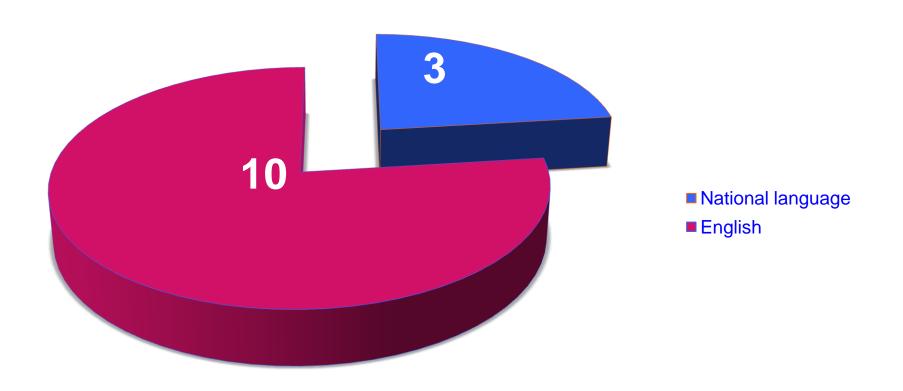
- Consultation document
- General Health Plan
- A situation analysis



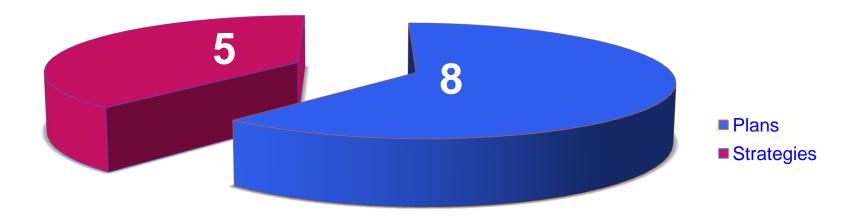
Language used in the documents



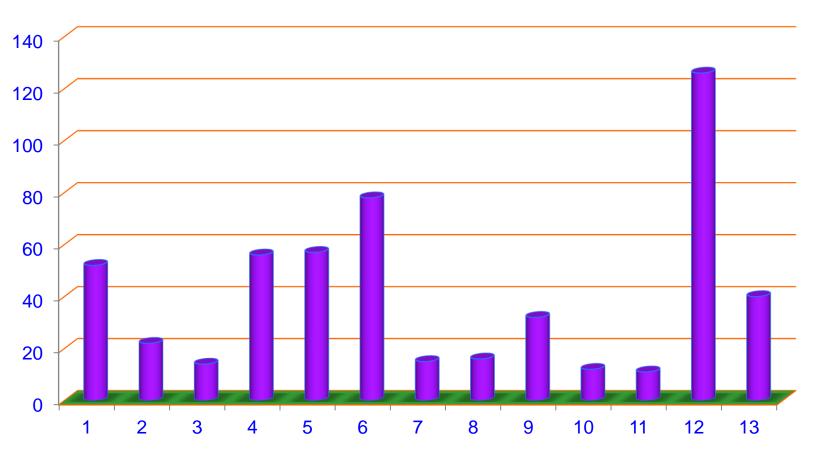
Total documents reviewed = 13 72%



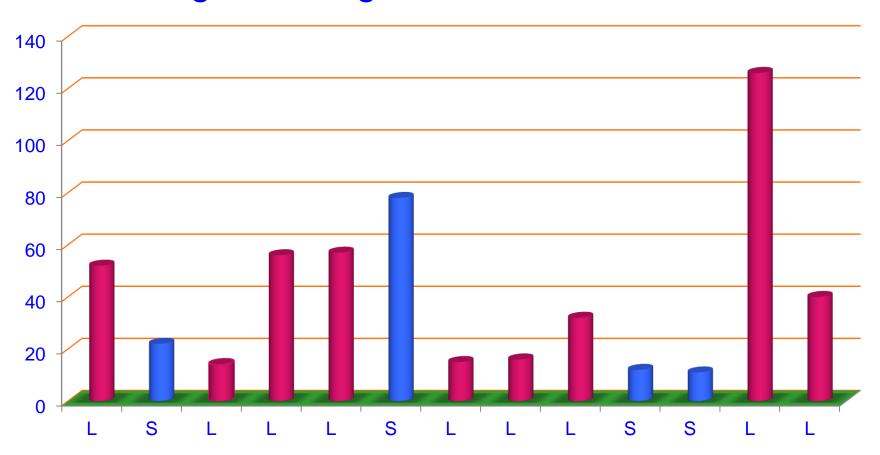
Plans and Strategies



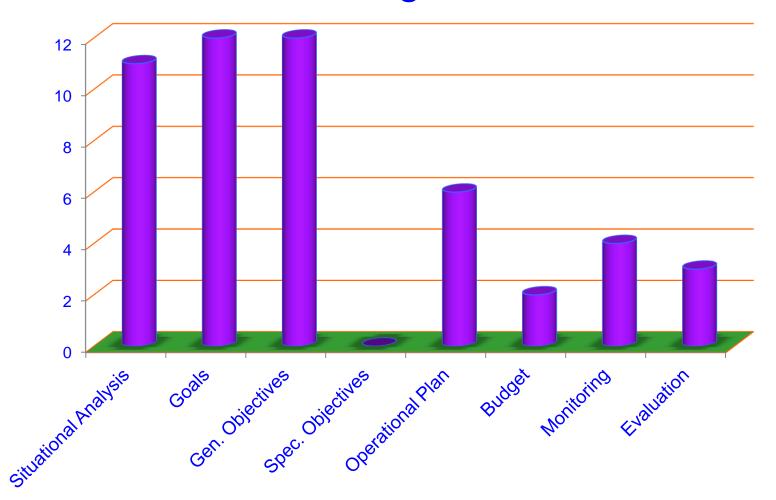
Number of pages



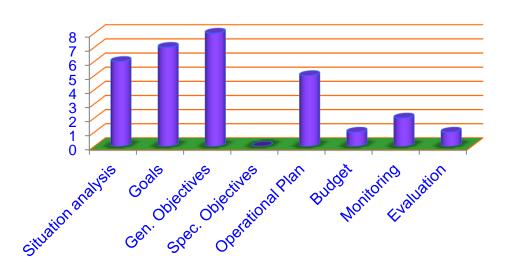
Pages for large and small Countries



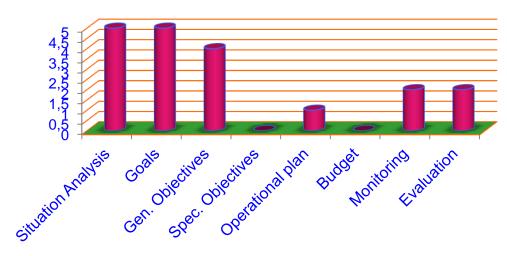
Plans/Strategies details



Plans

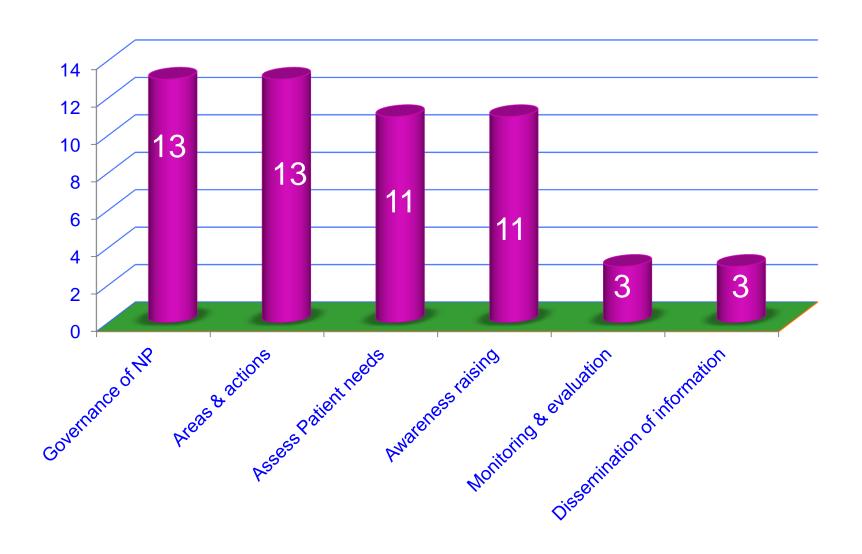


Strategy



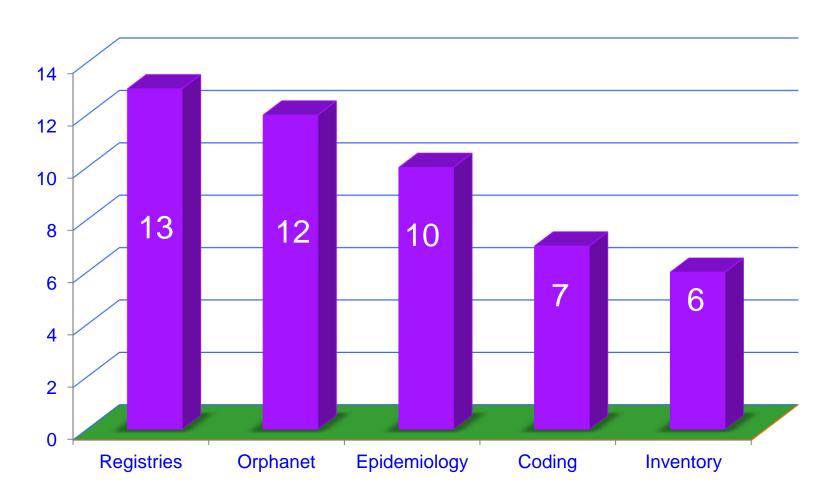
Plans or Strategies in the field of Rare Diseases

AREA 1

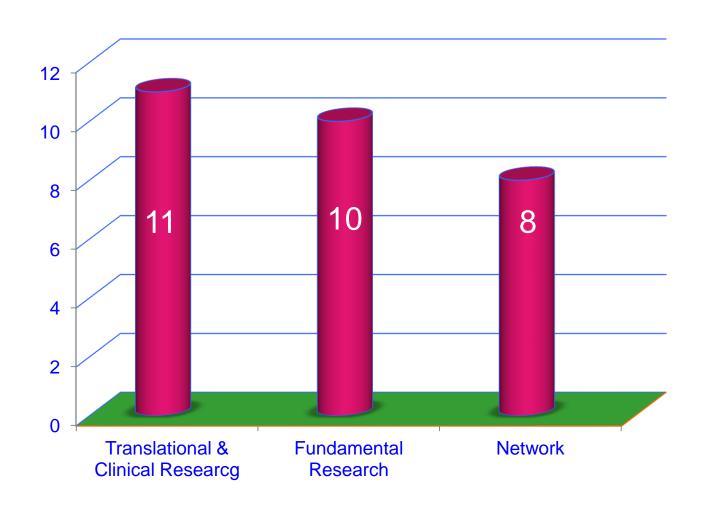


Definition, Codification and Inventoring of RD

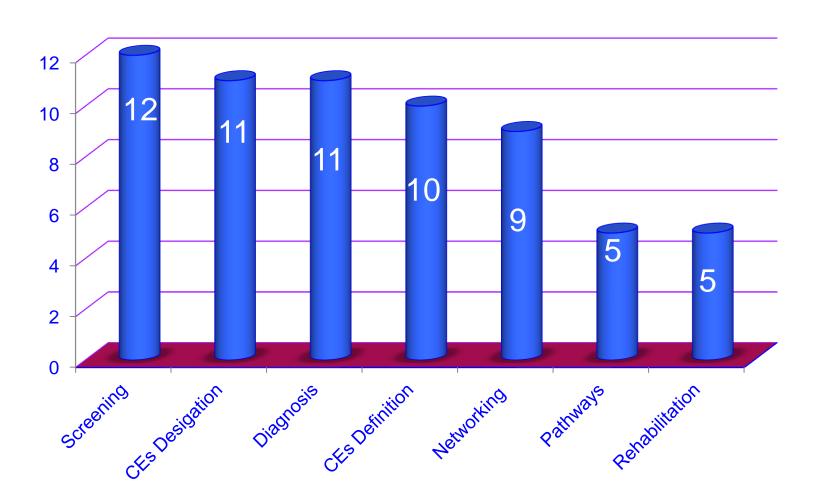
AREA 2



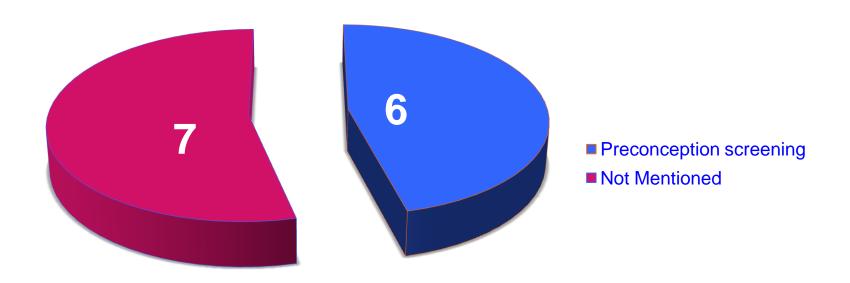
AREA 3 Research on Rare Diseases



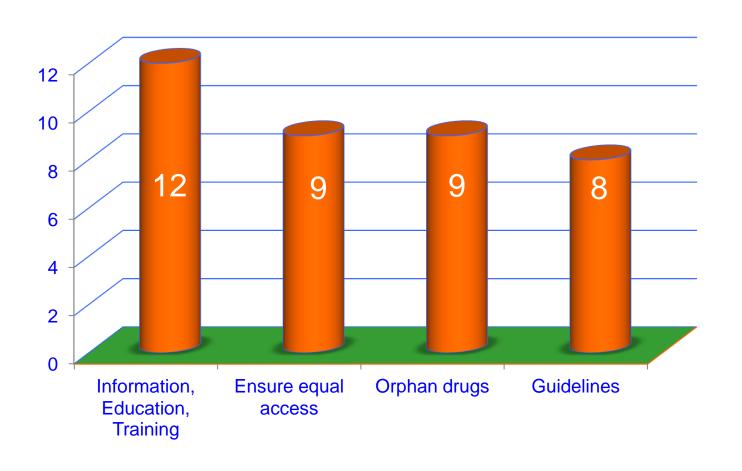
AREA 4 Ces & ERNs



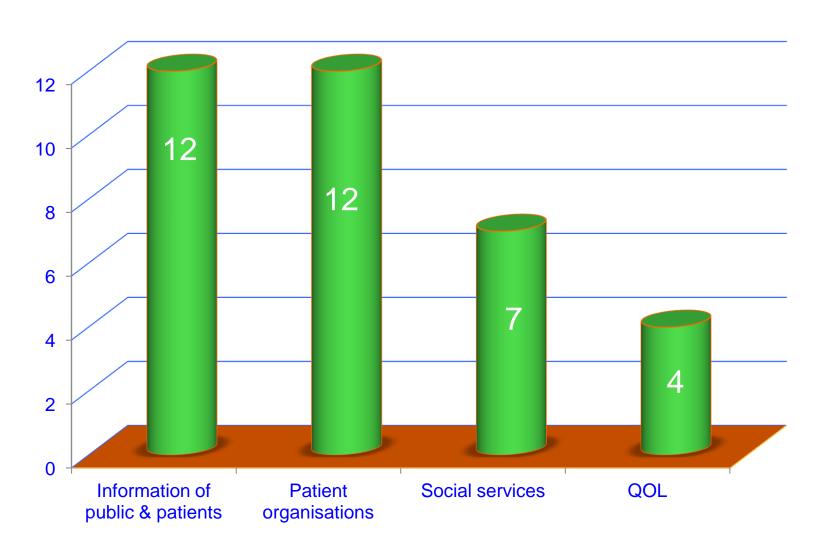
Primary prevention N = 13



AREA 5
Gathering Expertise on Rare Diseases at European level



AREA 6 Empowerment of Patient Organisations







Lights and shadows

Good efforts by all MS





Situation analysis

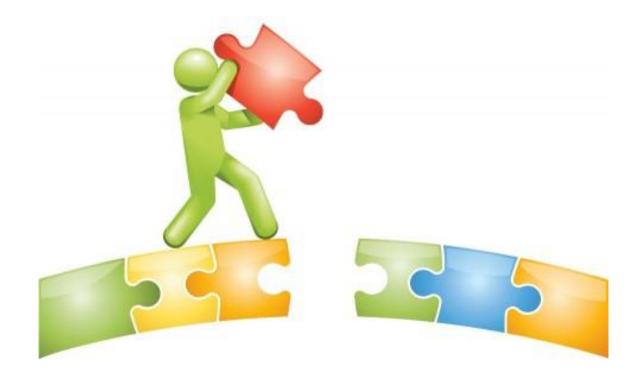


Prioritisation of needs



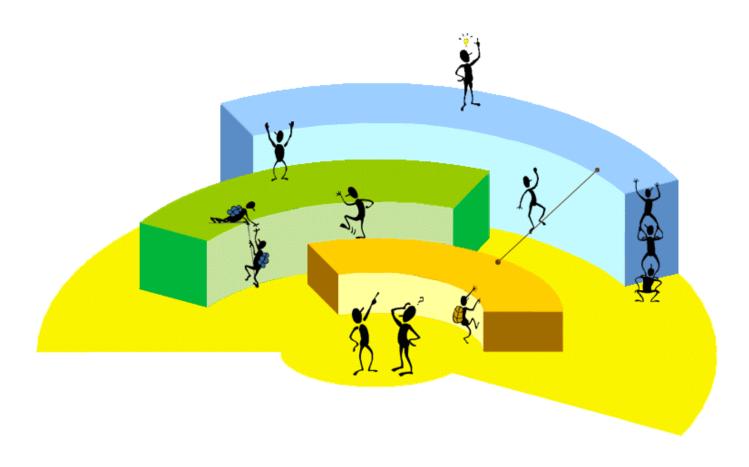
Planning

The planning needs to be strengthened, including planning of monitoring and evaluating activities.



Objectives

Definition of objectives needs attention, particularly specific objective.



Time

- Some plans are expired
- Some have no specified time
- Some are out-dated



Budgets

There is no plan without resources!



Where do we go from here?

Capacity building and development!





