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## WP4

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# Review the Plans/Strategies for Rare Diseases in Europe

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**EUCERD Joint Action Workshop "EUROPLAN National Plans/Strategies capacity building activities"**

*8 May 2014 - Federal Ministry of Health, Berlin*

# 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

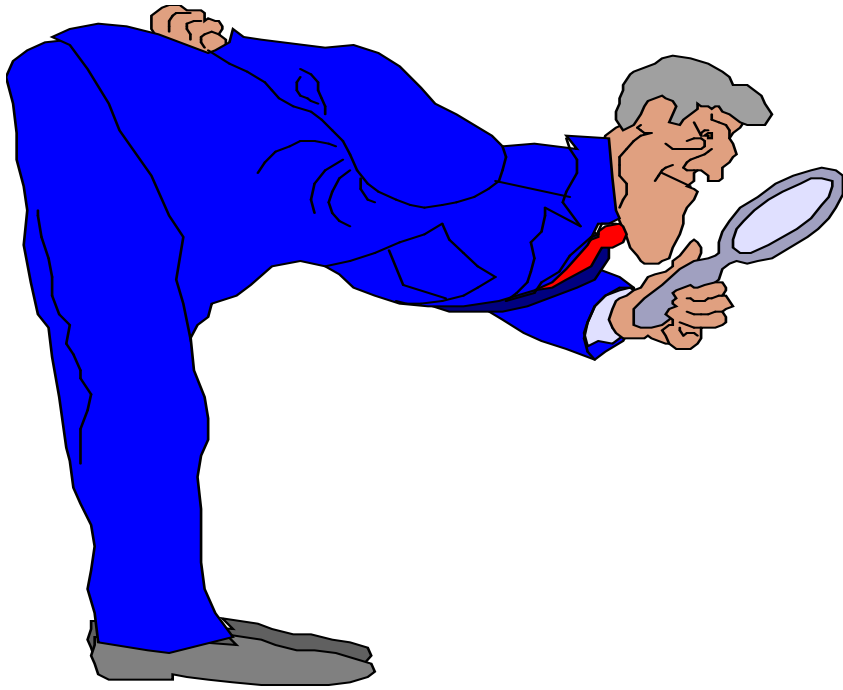


# Situation analysis

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 activities, strategies and resources spelled out in a document with the aim of reaching one or more objectives.

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

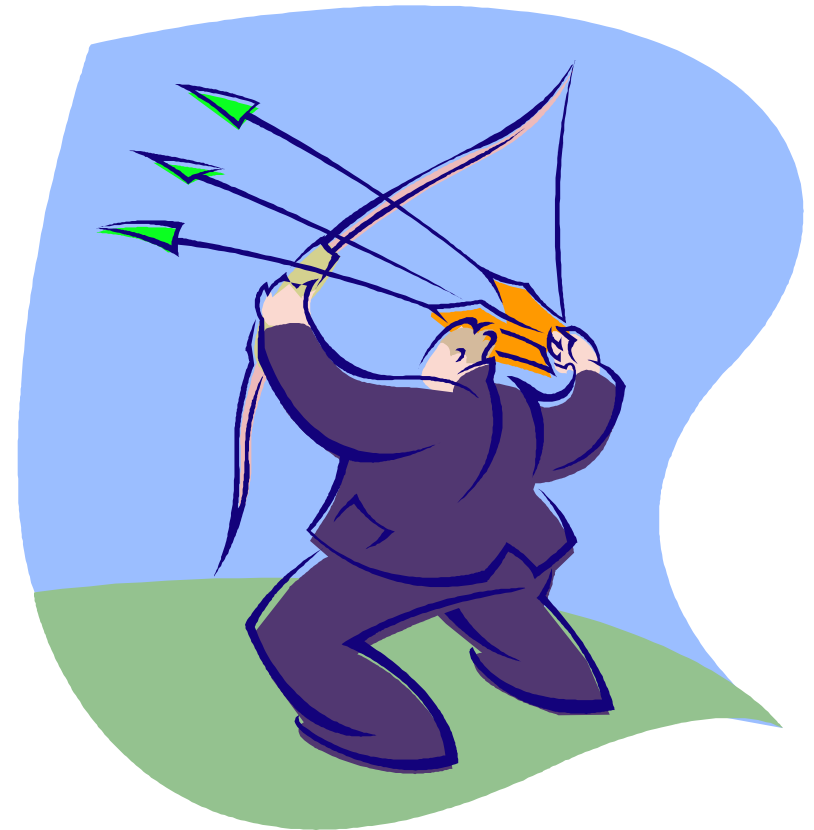
## Goals:

- 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

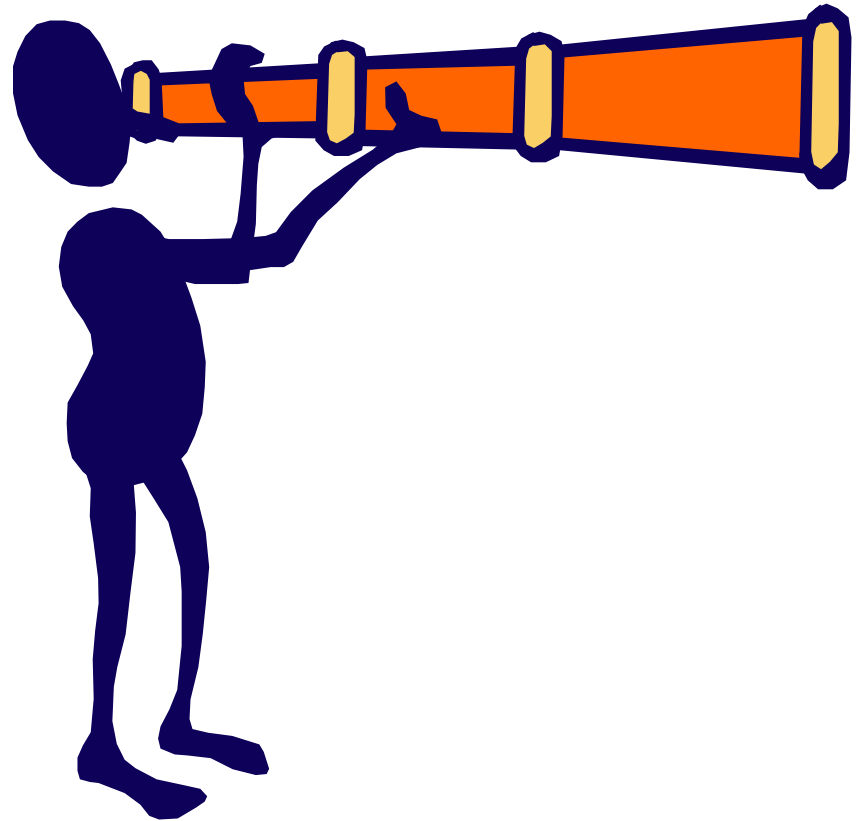
**T** Timely



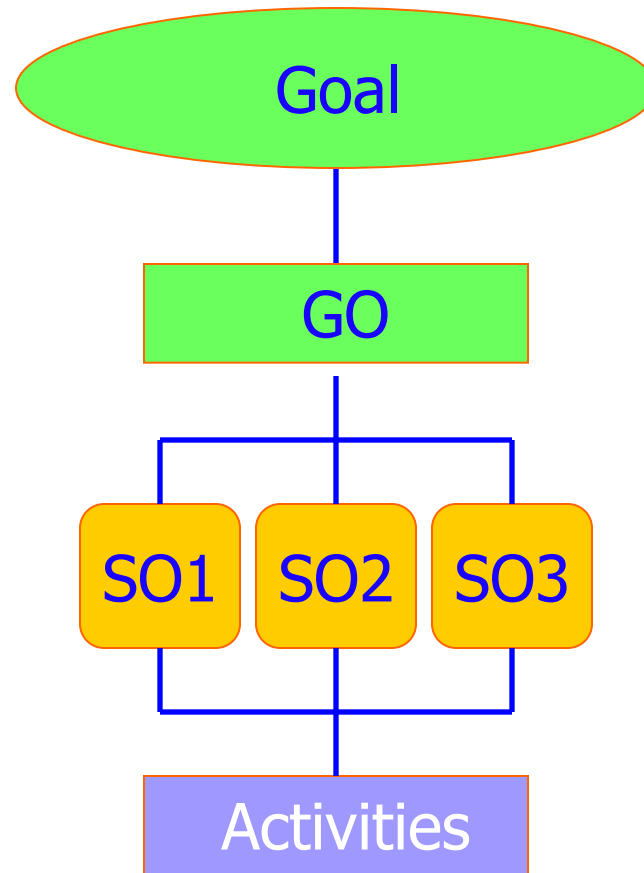
# Measurability of SO

The SO must answer to these questions:

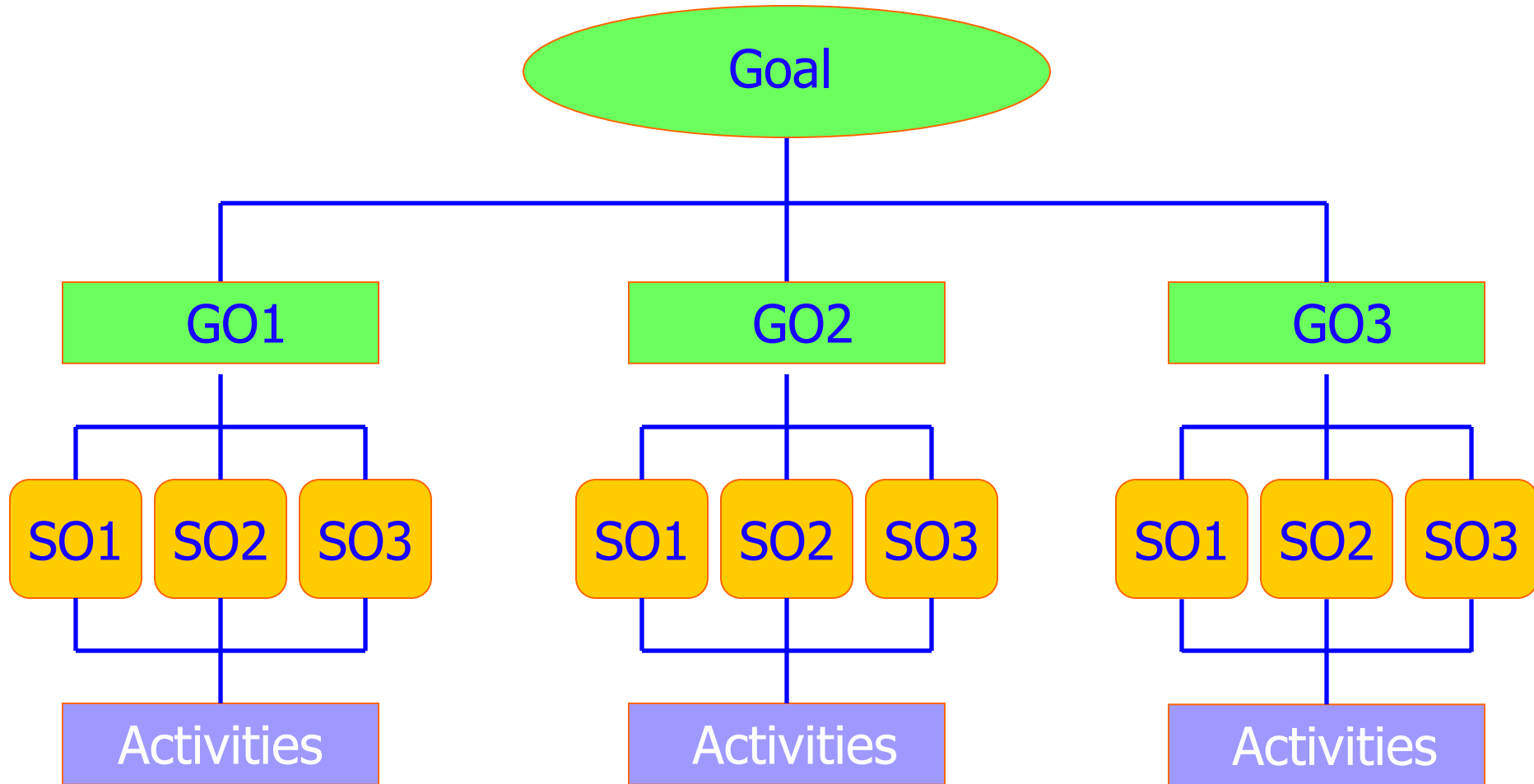
- What?
- How much?
- When?
- Who?
- Where?



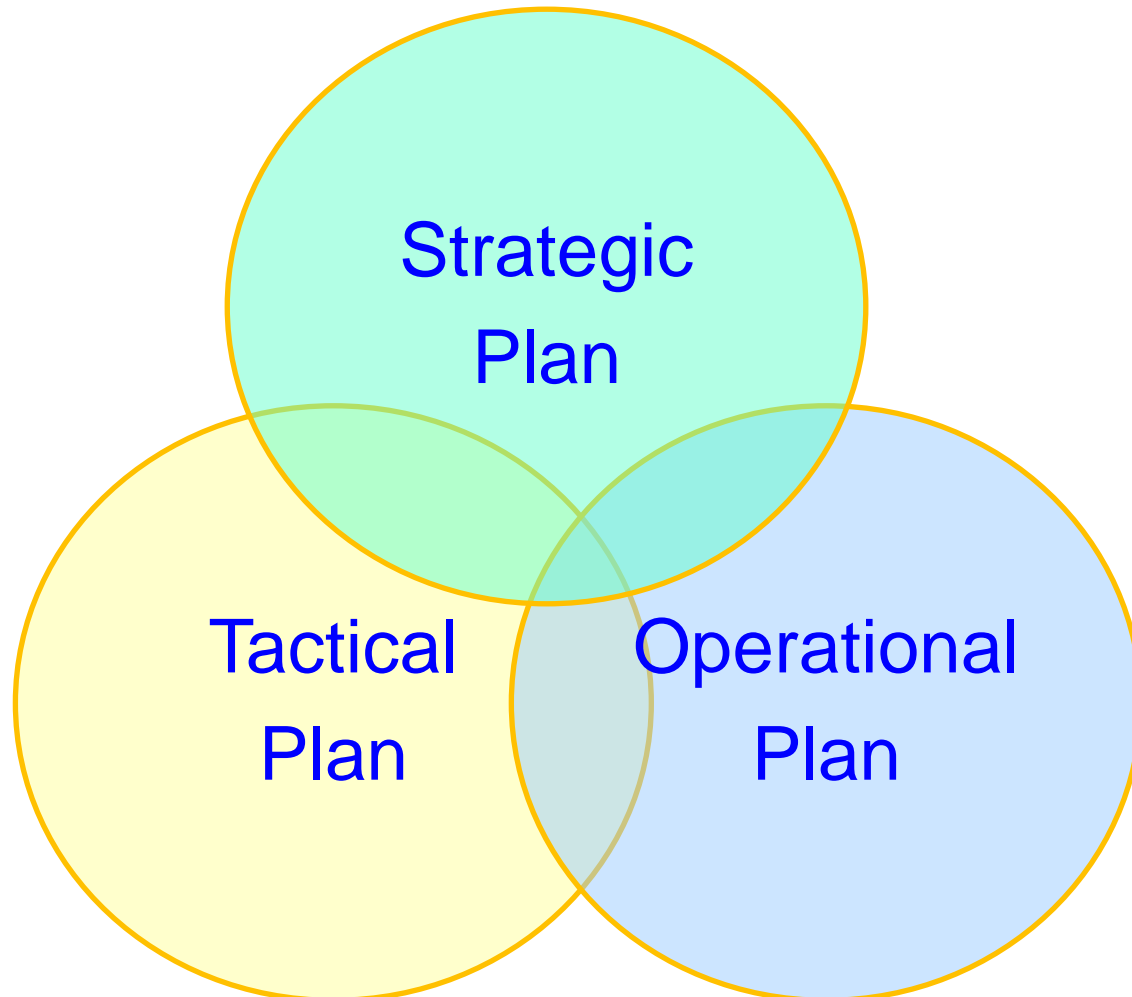
# Hierarchy of objectives



# 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

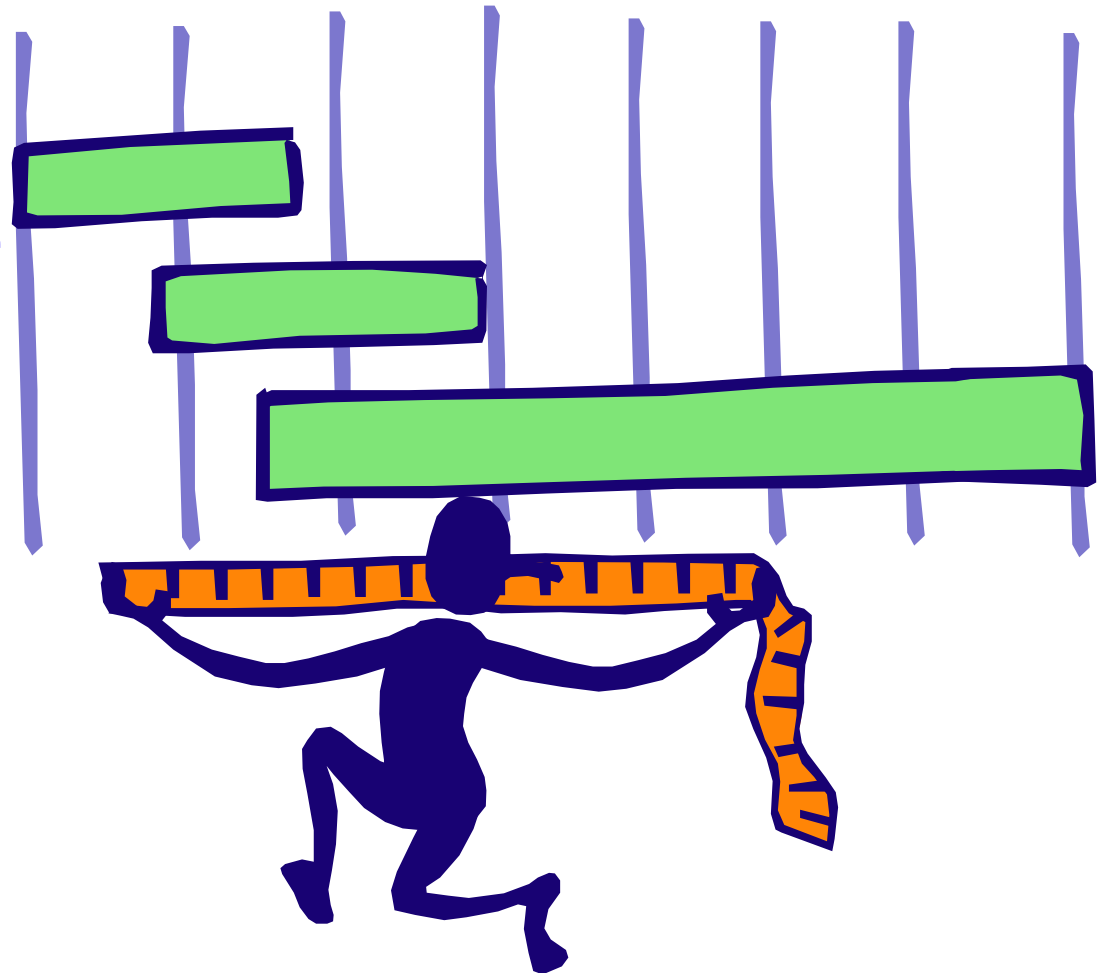
- Activity: what
- Resources: with what means
- Time: when
- Place: where
- Strategy: how
- Budget: how much
- Foreseeable risks
- Evaluation plan



# Evaluation

➤ To measure

➤ To weight





# Types of evaluation

- Monitoring
- Supervision
- Evaluations:
  - process
  - result
  - impact

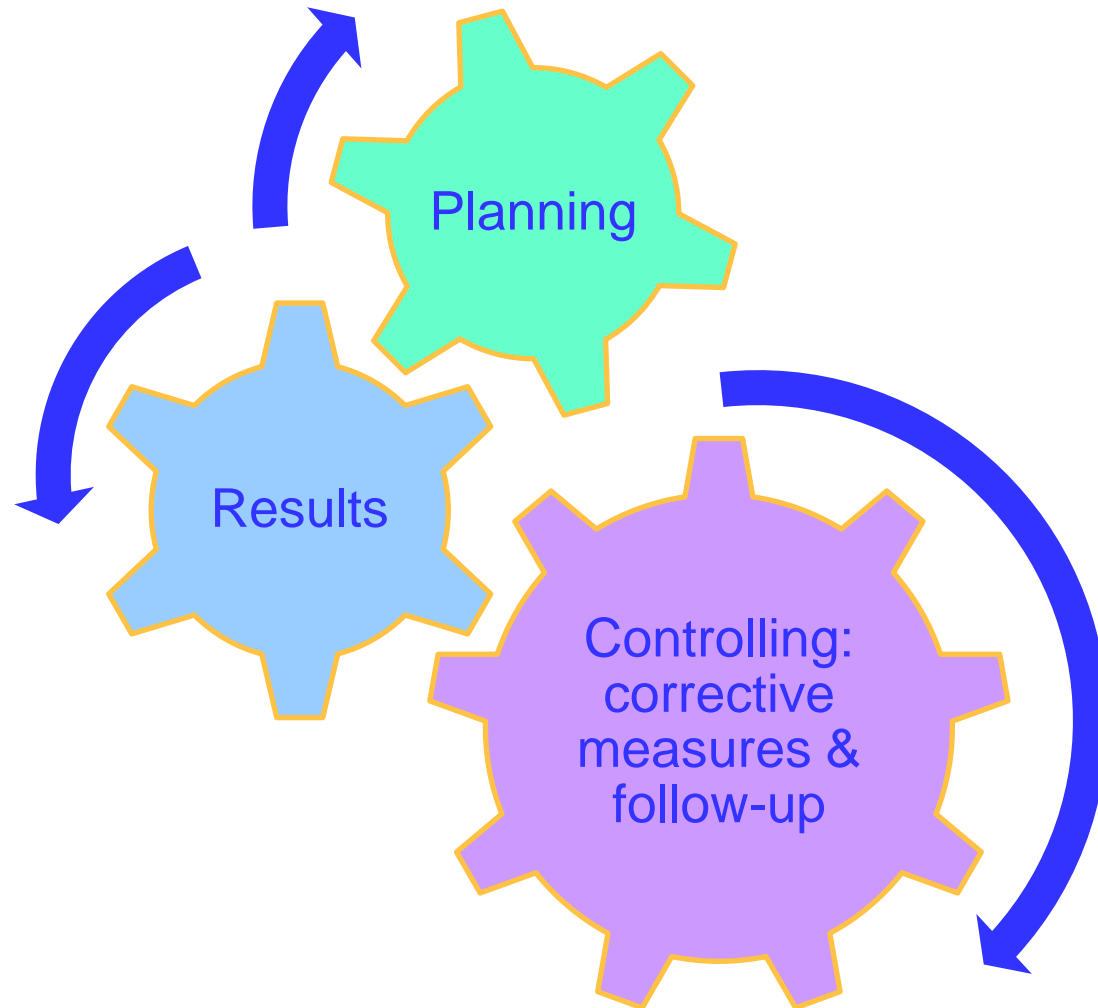


# The indicator is...

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



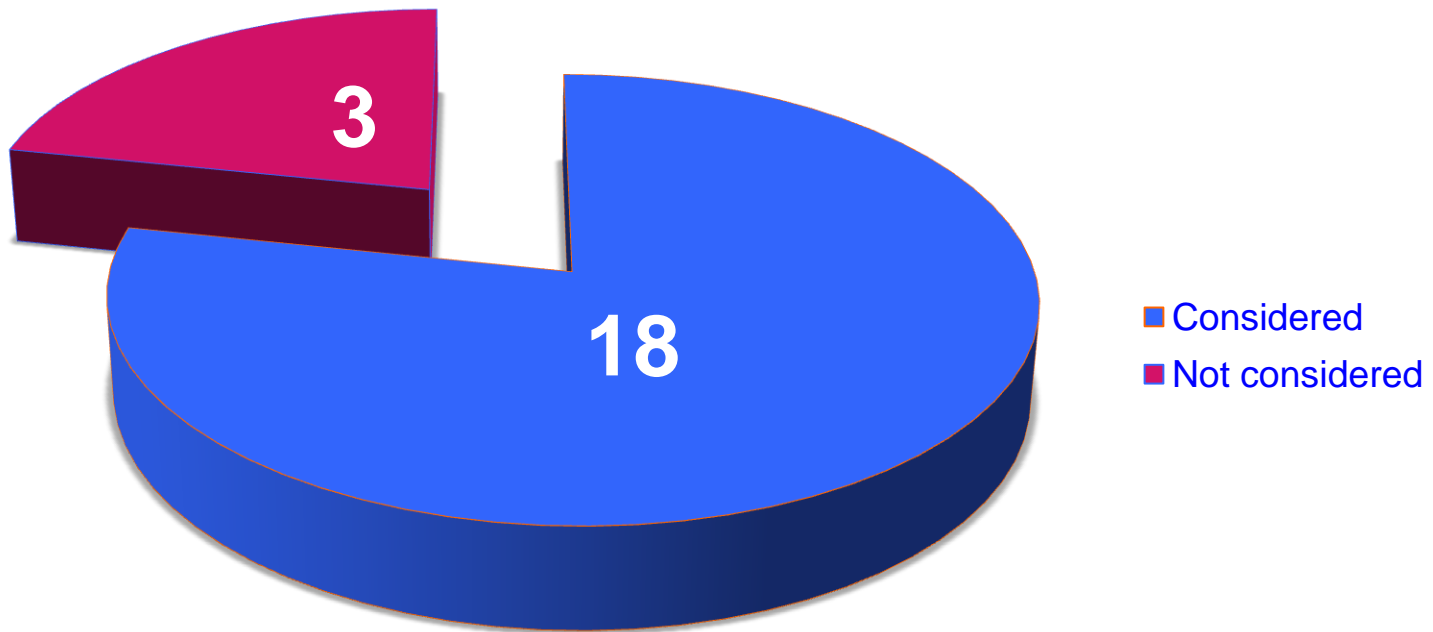
# Panning and Controlling... an unending phenomenon



# Main Findings



Total entries for review = 21

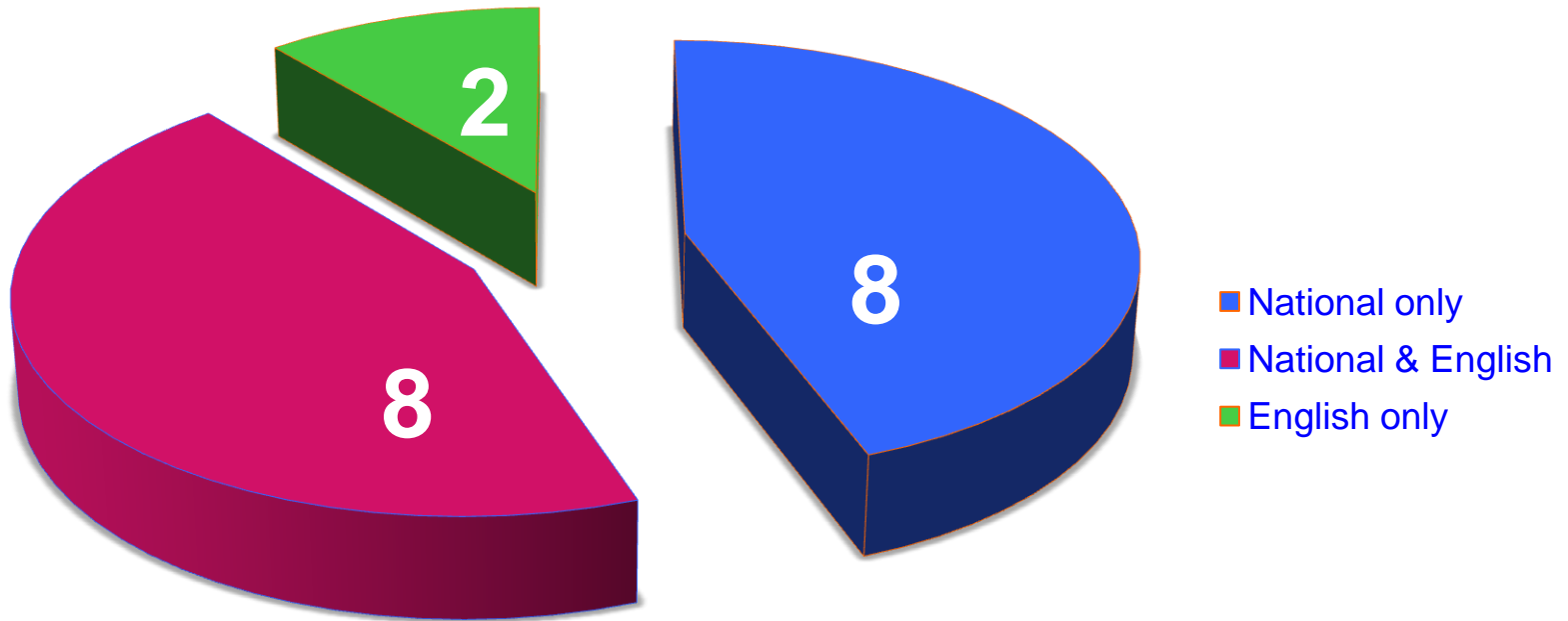


## Reasons for exclusion from review

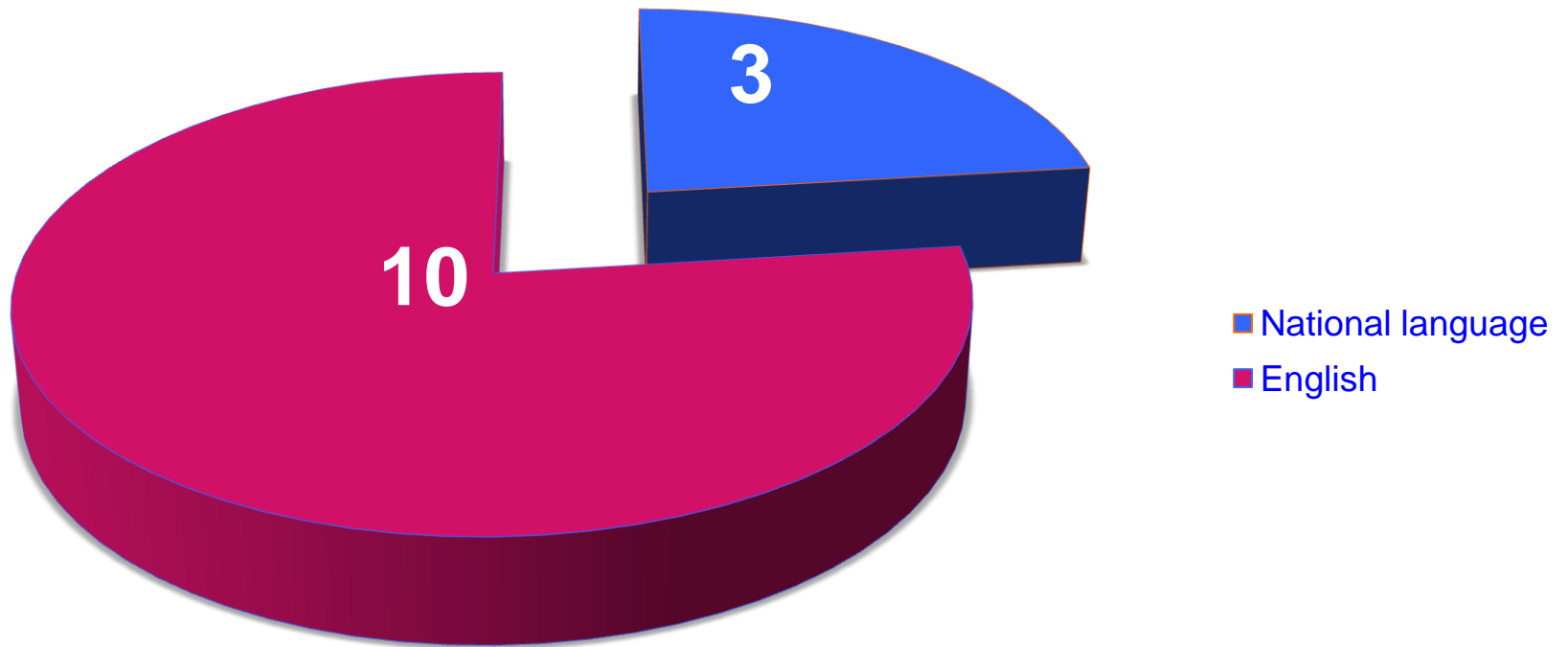
- Consultation document
- General Health Plan
- A situation analysis



# Language used in the documents

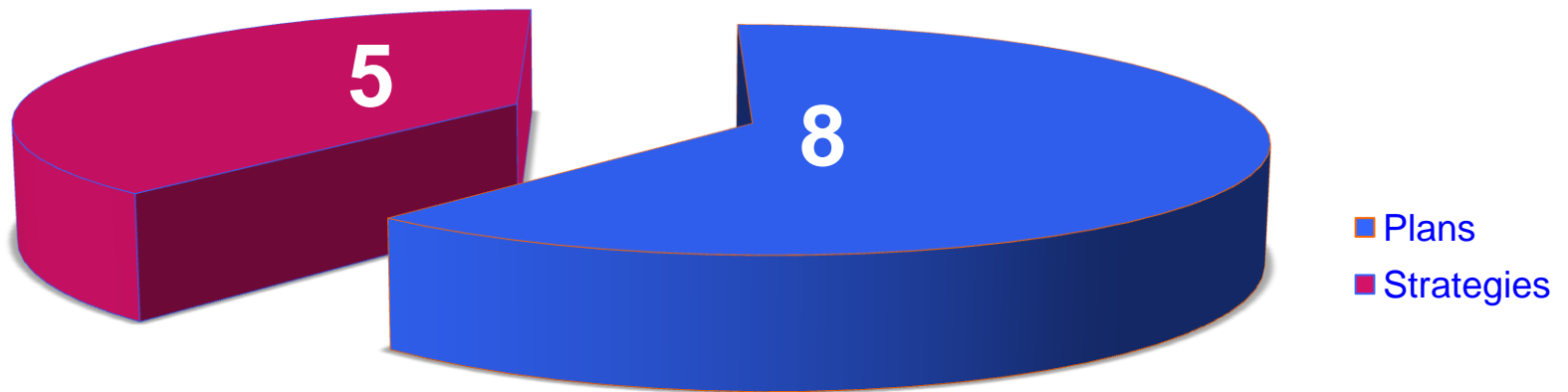


Total documents reviewed = 13  
72%

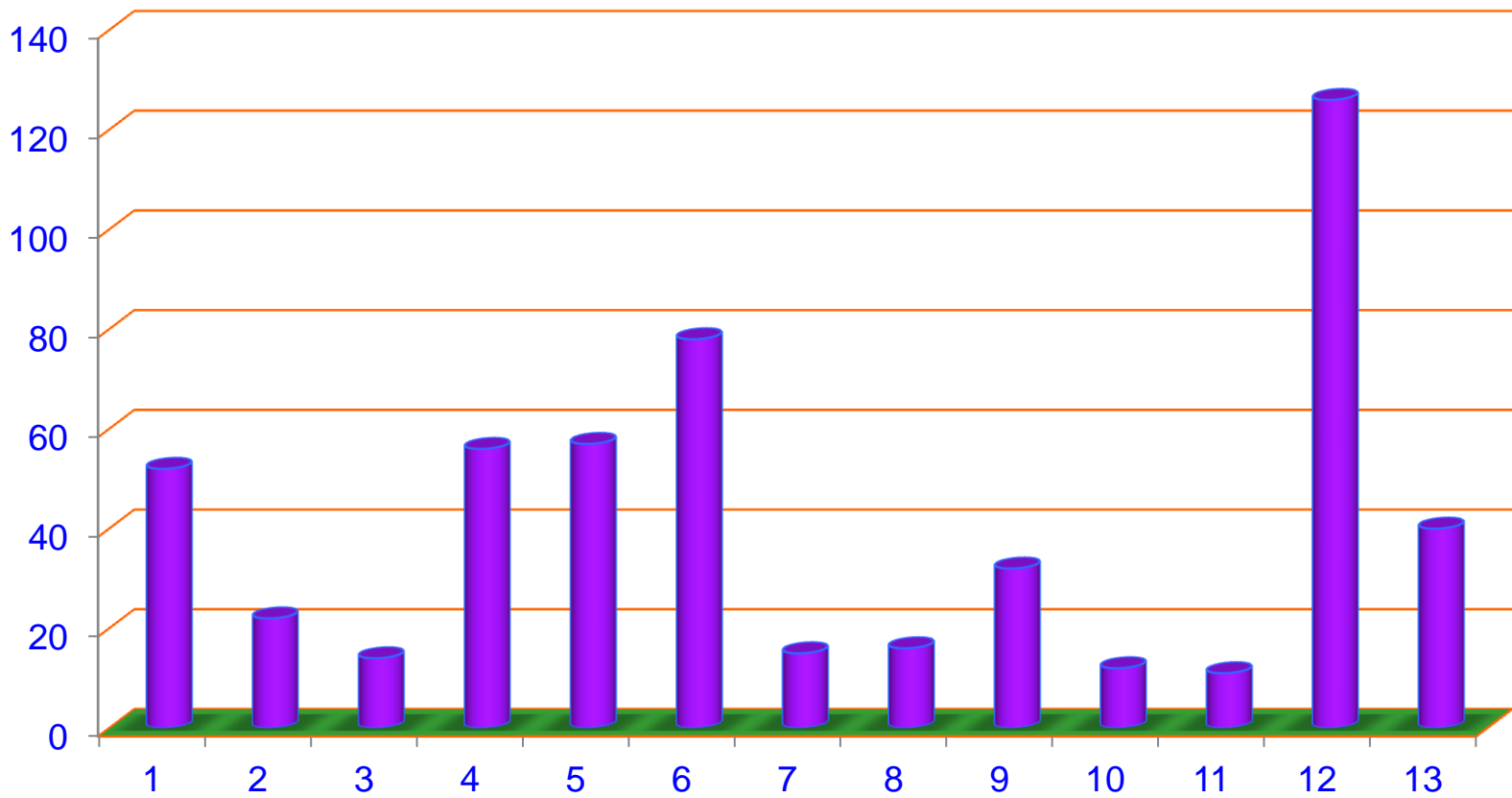




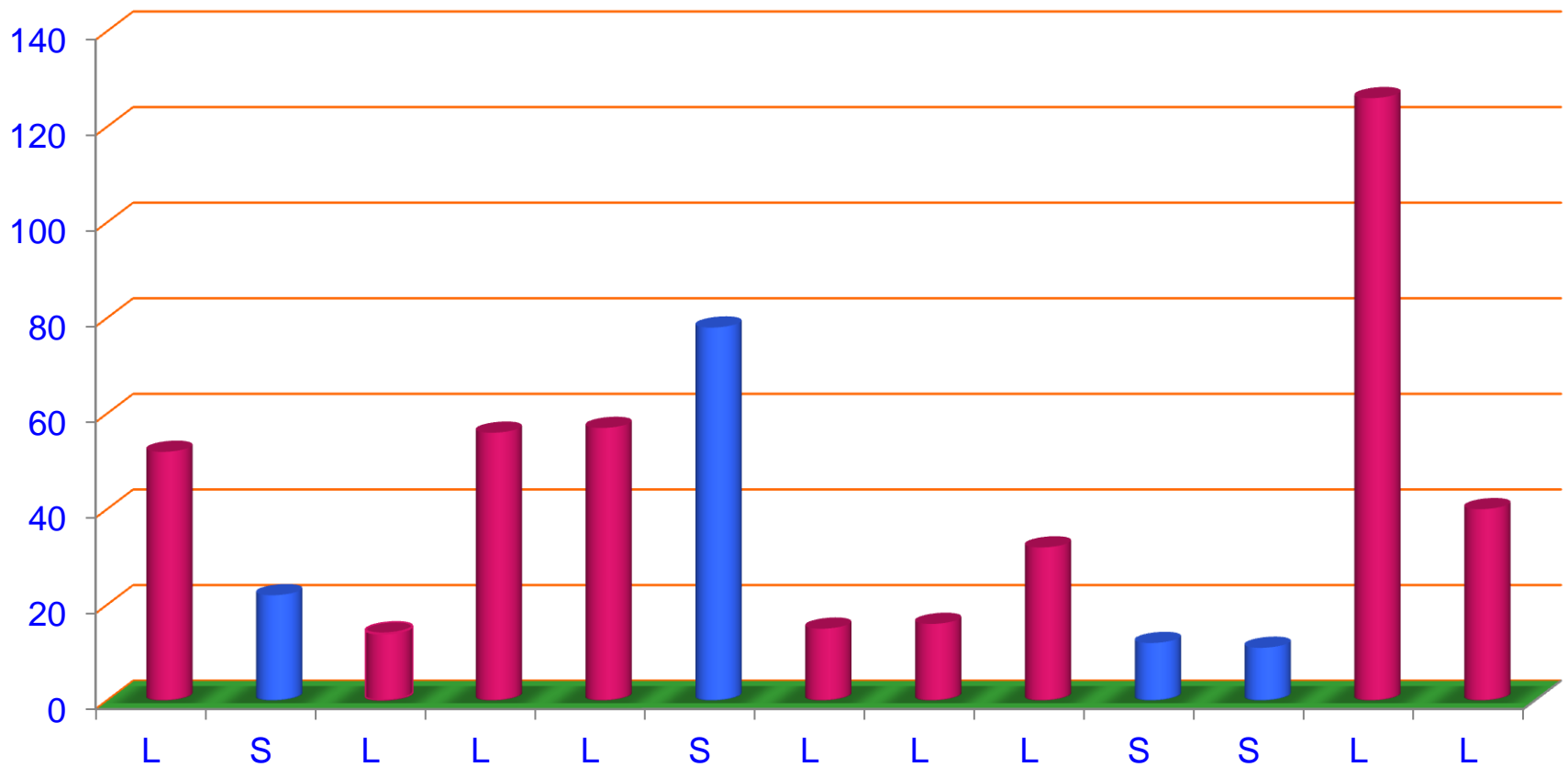
# Plans and Strategies



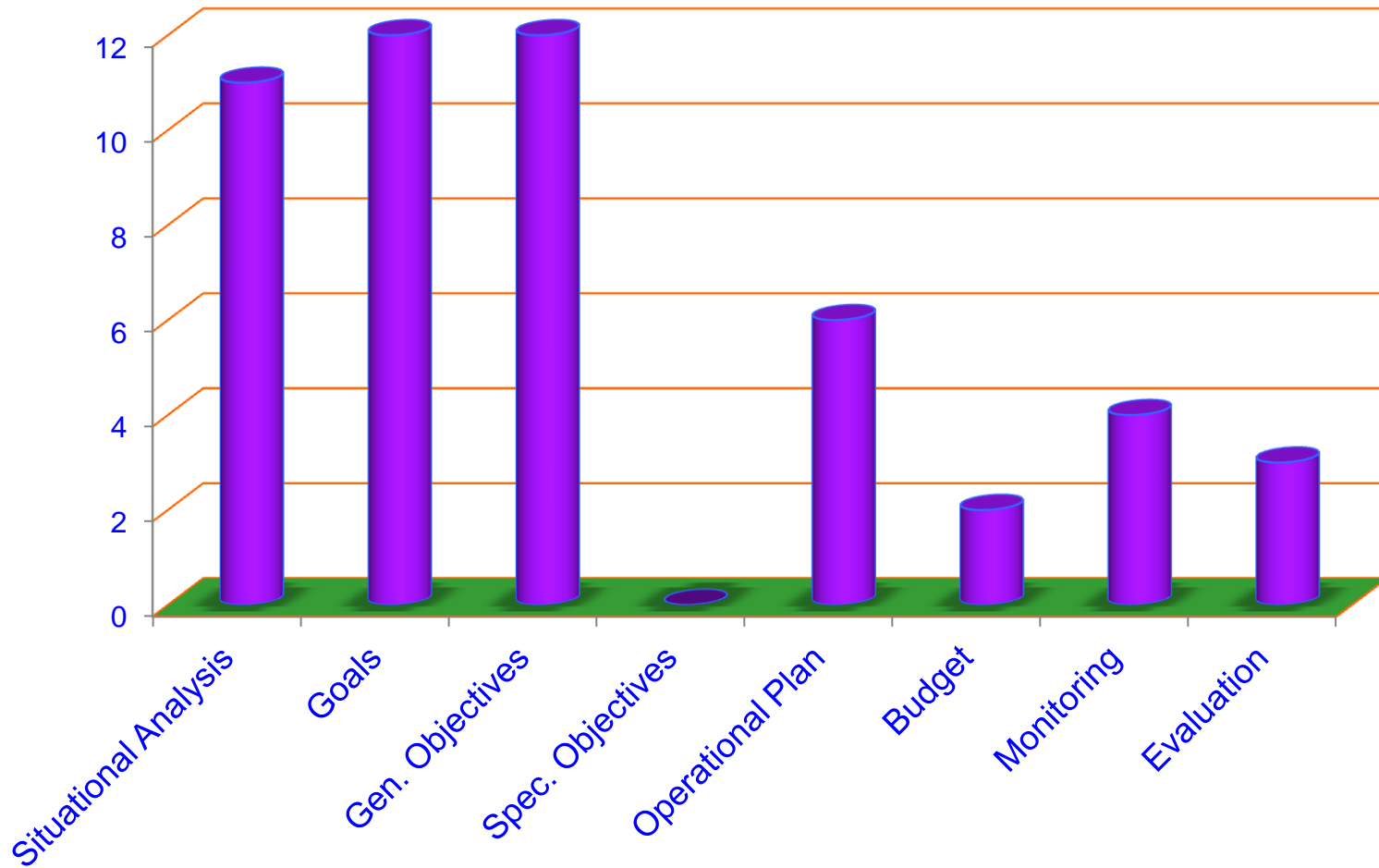
# Number of pages



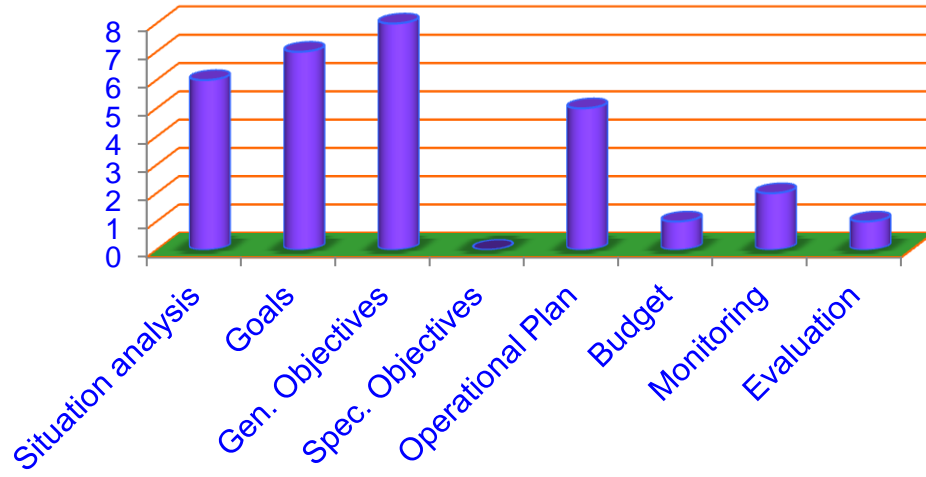
# Pages for large and small Countries



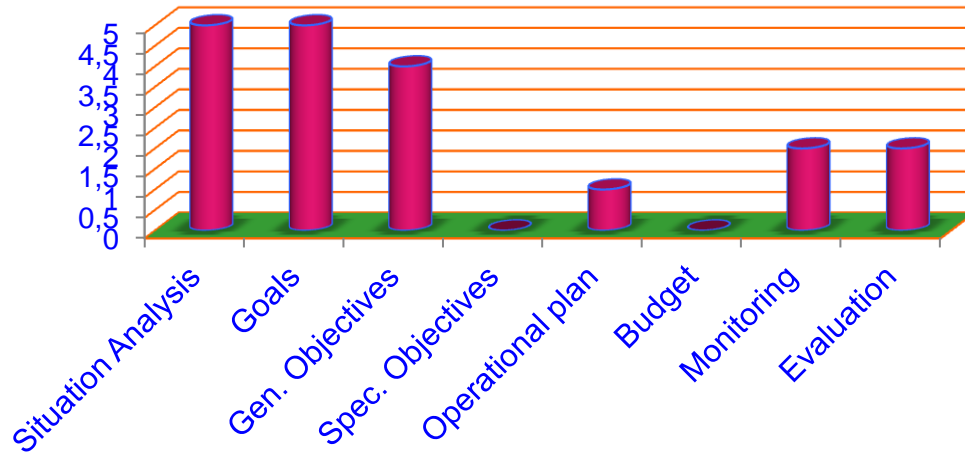
# Plans/Strategies details



# Plans

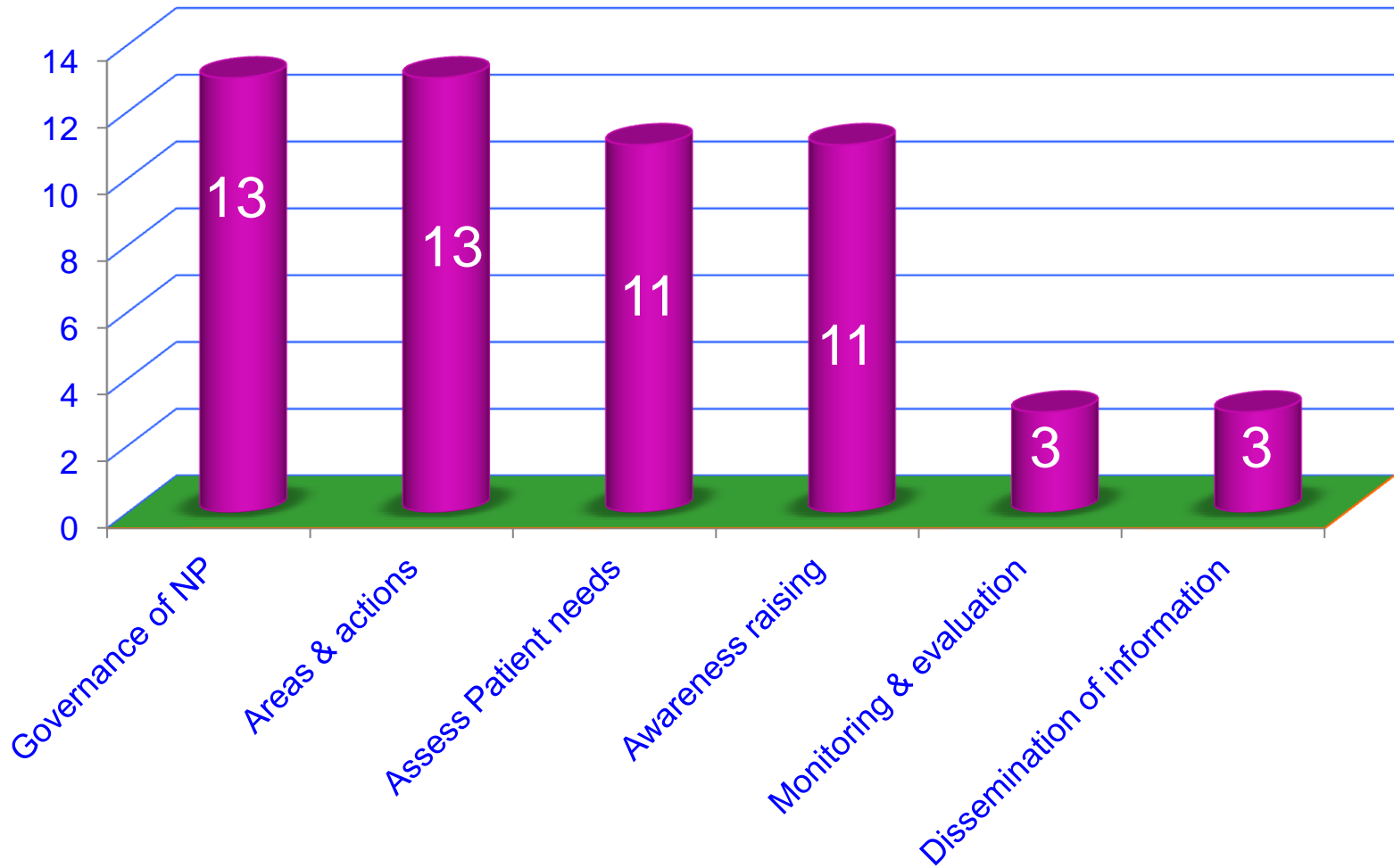


# Strategy



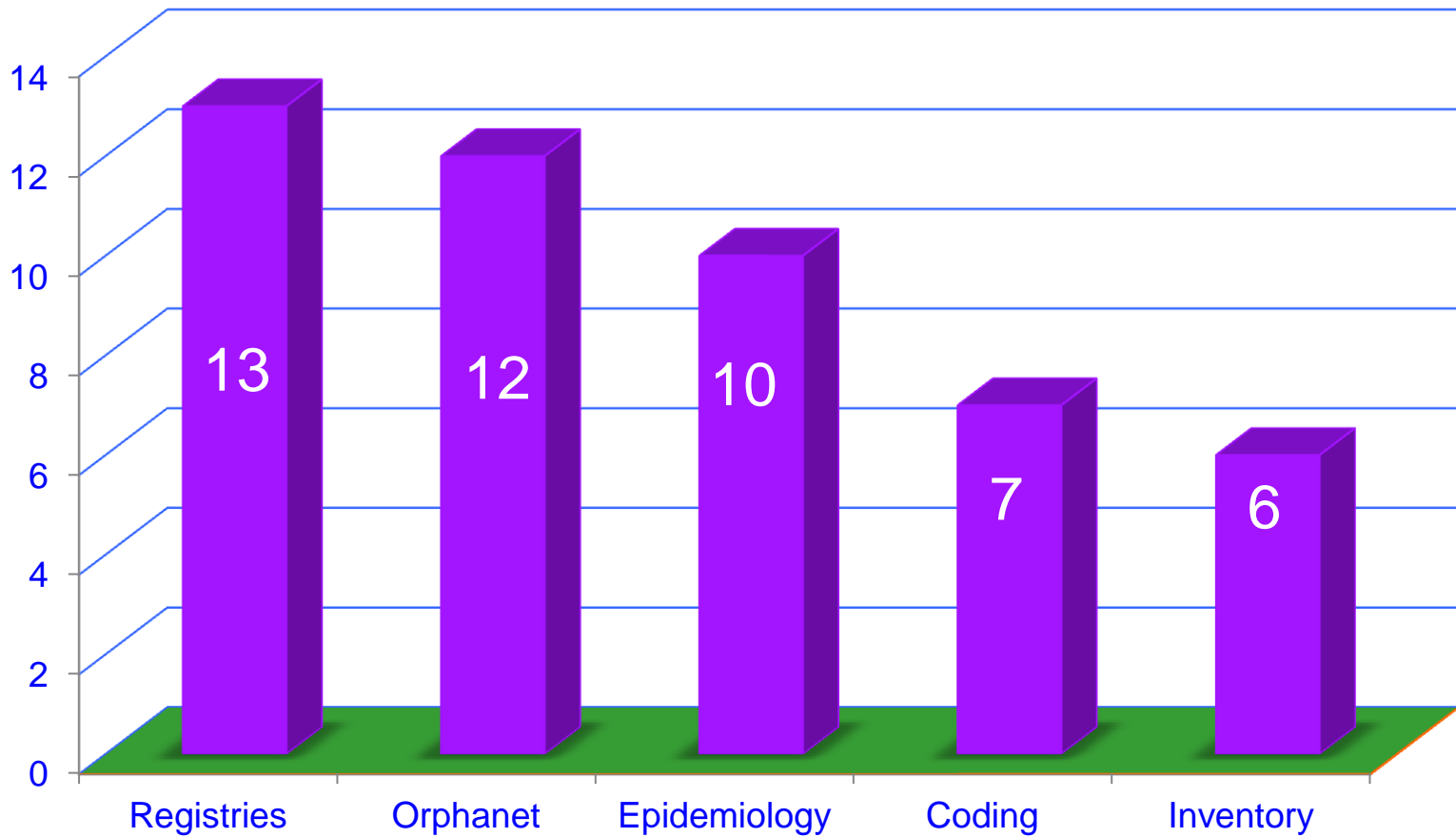
# AREA 1

## Plans or Strategies in the field of Rare Diseases



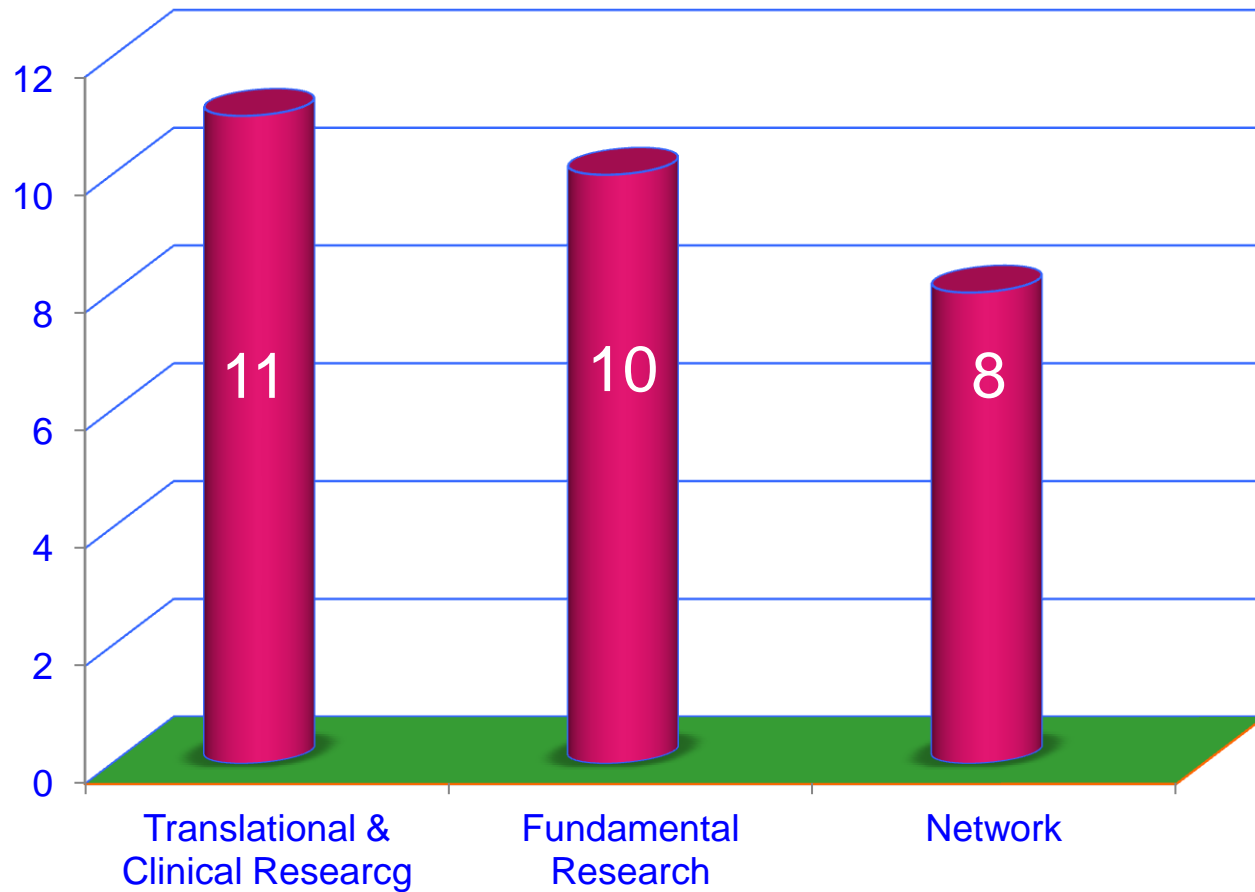
# AREA 2

## Definition, Codification and Inventoring of RD



# AREA 3

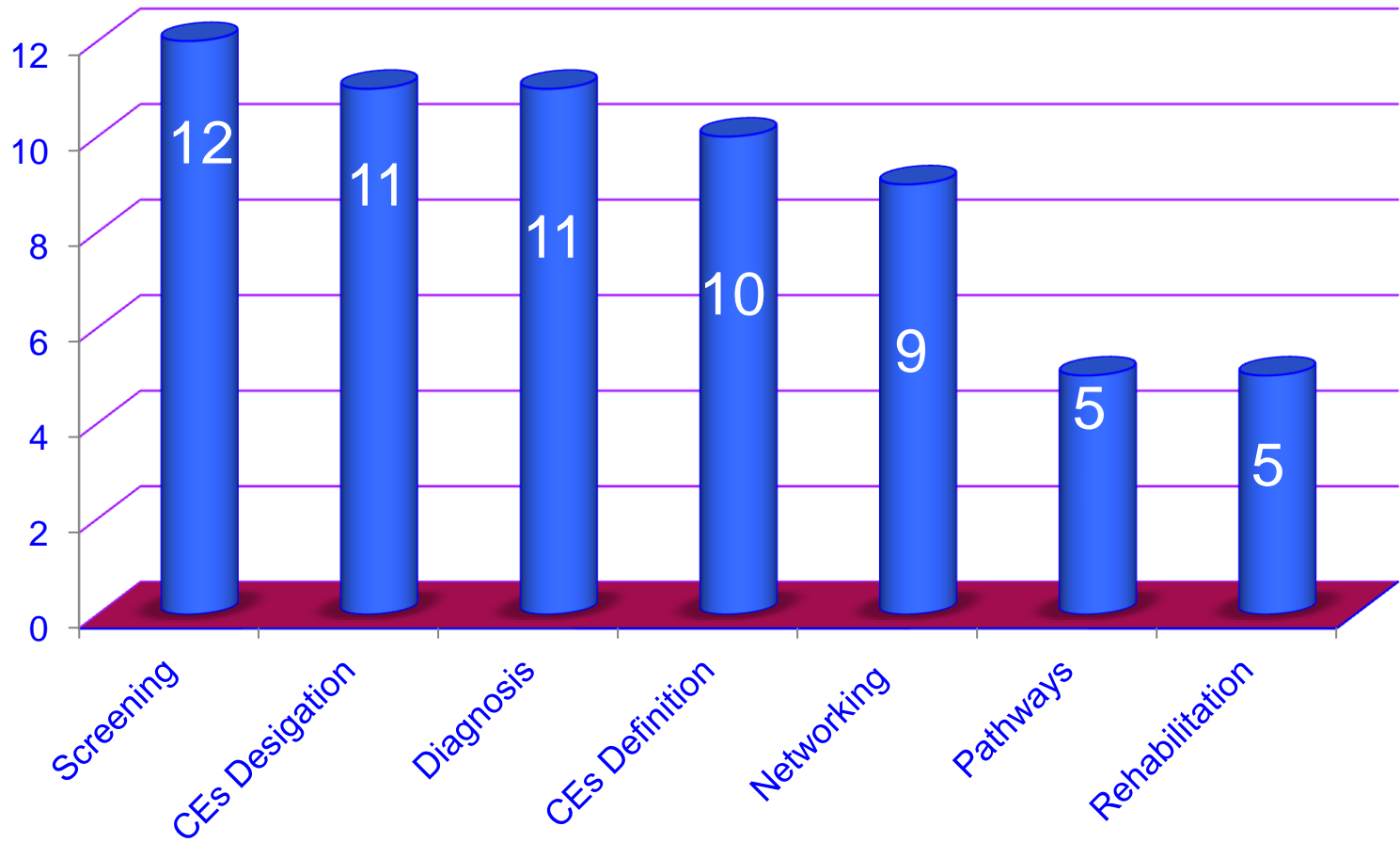
## Research on Rare Diseases



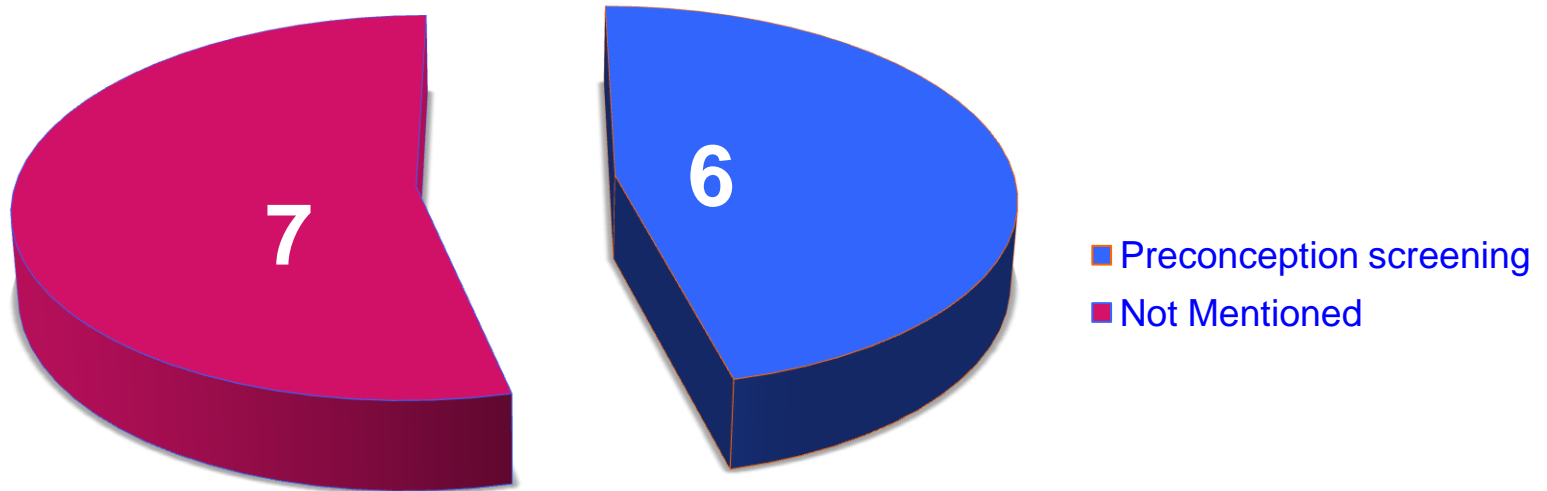


# AREA 4

## Ces & ERNs

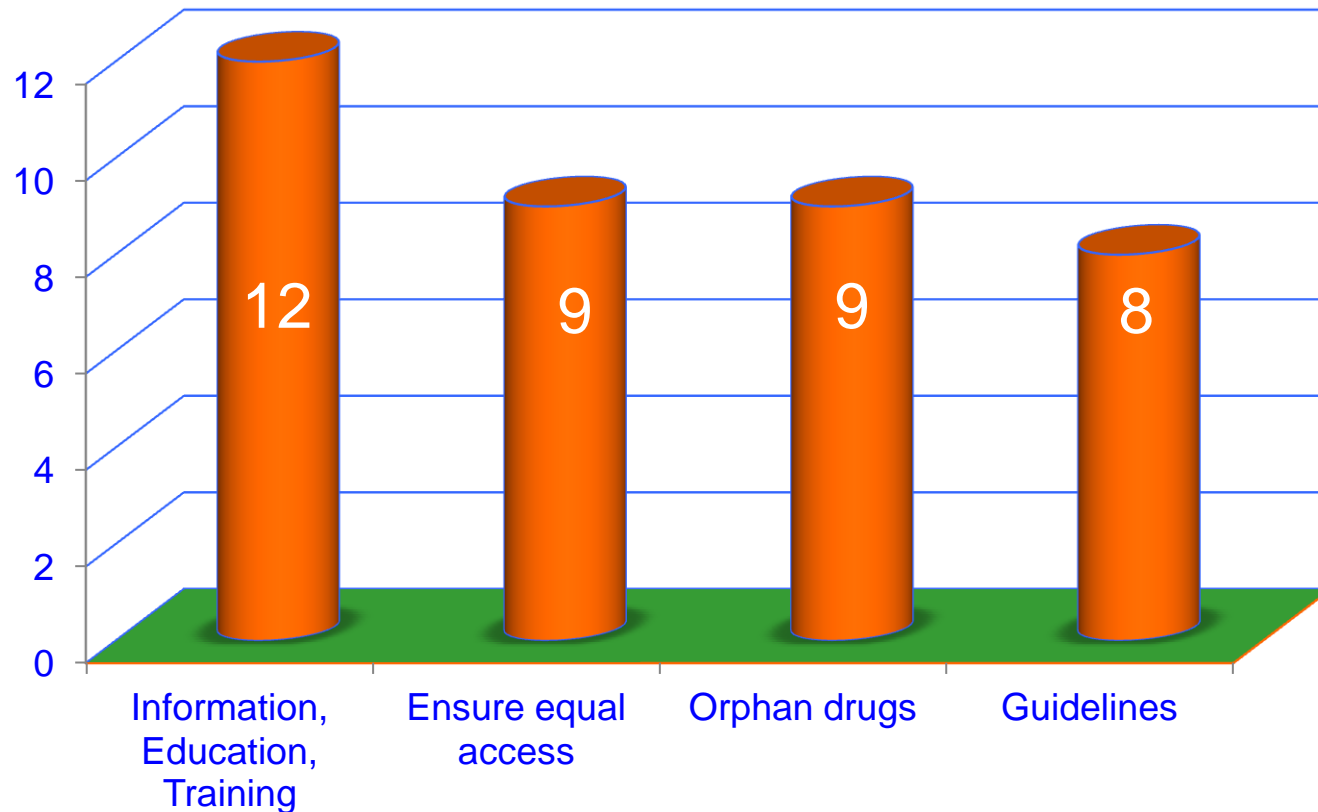


# Primary prevention N = 13



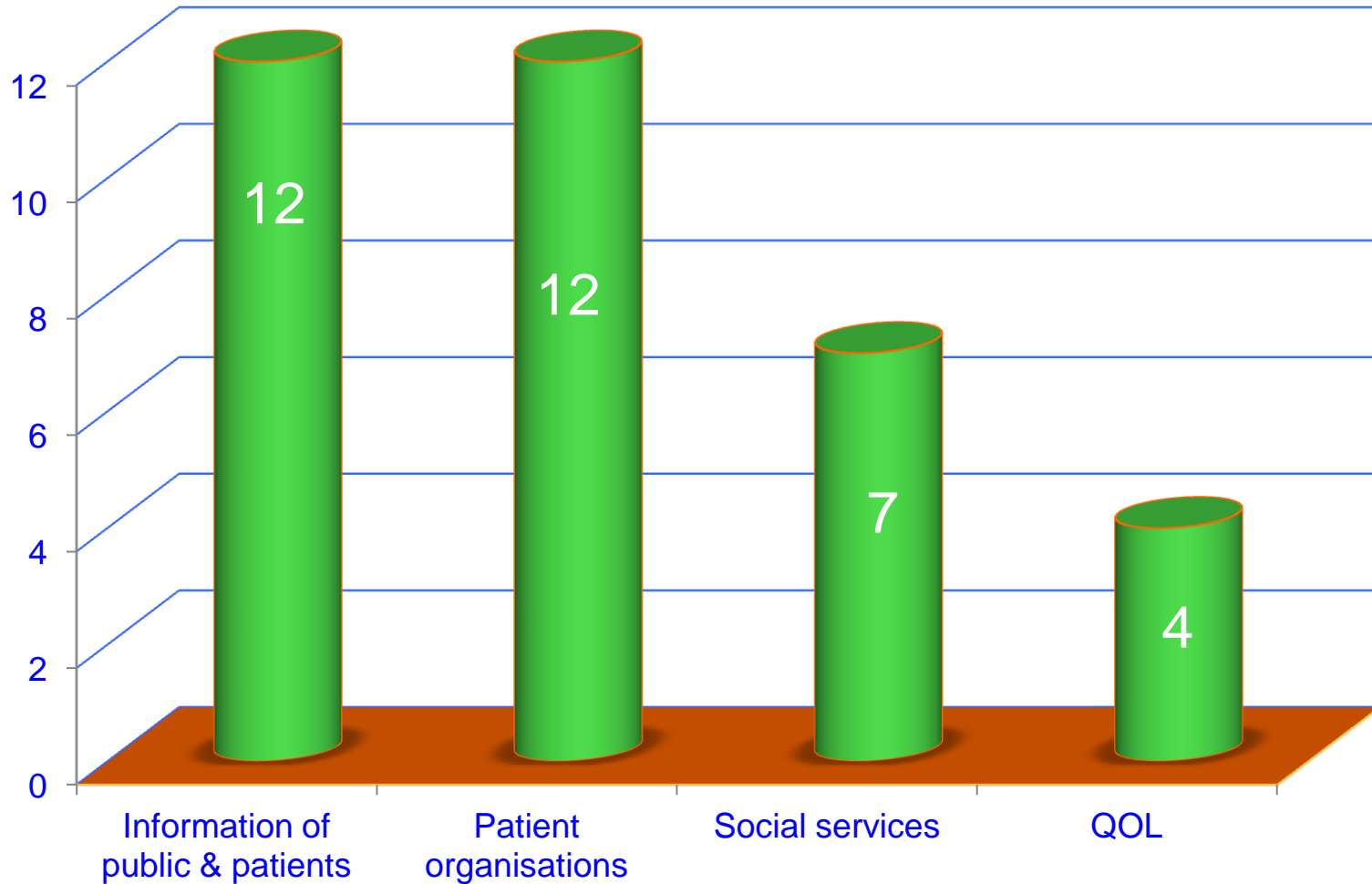
# AREA 5

## Gathering Expertise on Rare Diseases at European level



# AREA 6

## Empowerment of Patient Organisations



A landscape photograph showing a green field in the foreground, a line of trees in the middle ground, and a bright sun rising on the horizon. The sky is a mix of blue and orange, with a crescent moon visible in the upper right. The overall scene is hazy and atmospheric.

AREA 7  
Sustainability

Still hazy...





Lights and shadows

Good efforts by all MS





# Planning

Define the levels!





# Situation analysis



# Prioritisation of needs



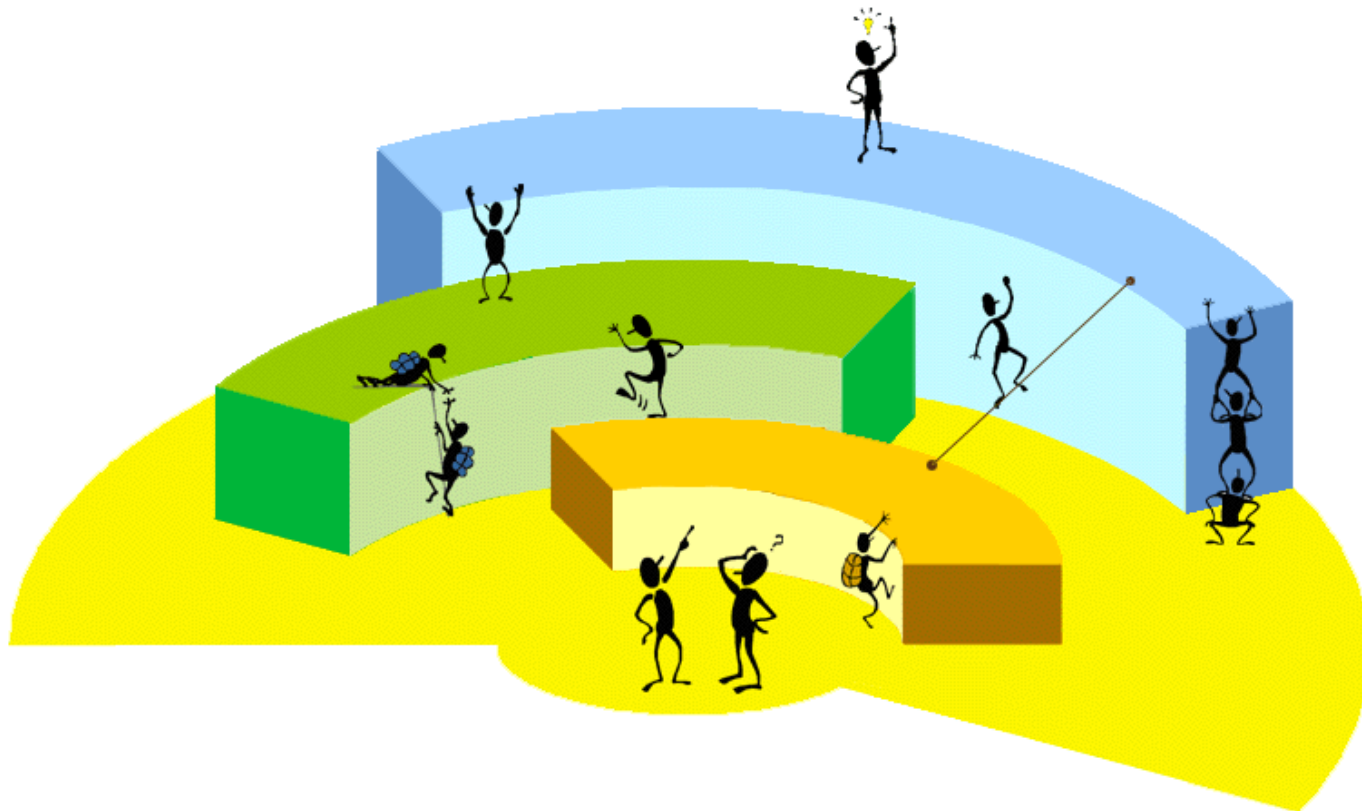
# Planning

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!







“When planning for a year,  
plant corn.  
When planning for a decade,  
plant trees.  
When planning for life,  
train and educate people.”

*Chinese proverb*





Thank you !