European Reference Networks

eUROGEN

(ERN for Rare and Complex Urogenital Diseases and Conditions)

Quality assessment, monitoring and evaluation of the networks

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Health

Conflict of interest disclosure

I have no actual or potential conflict of interest in relation to this program/presentation

ERN monitoring and assessment system - introduction

- Continuous monitoring of agreed indicators
- Periodical self-assessment and reporting of the ERNs and HCPs
- Periodical assessment / validation of specific criteria of the HCP

Progress

June 17 to March 18

- ERN Working Group proposal & initial agreement

May 18

- Merger of Working Groups of the ERN CG and ERN Board
- Qualitative analysis on the initial 41 set of indicators

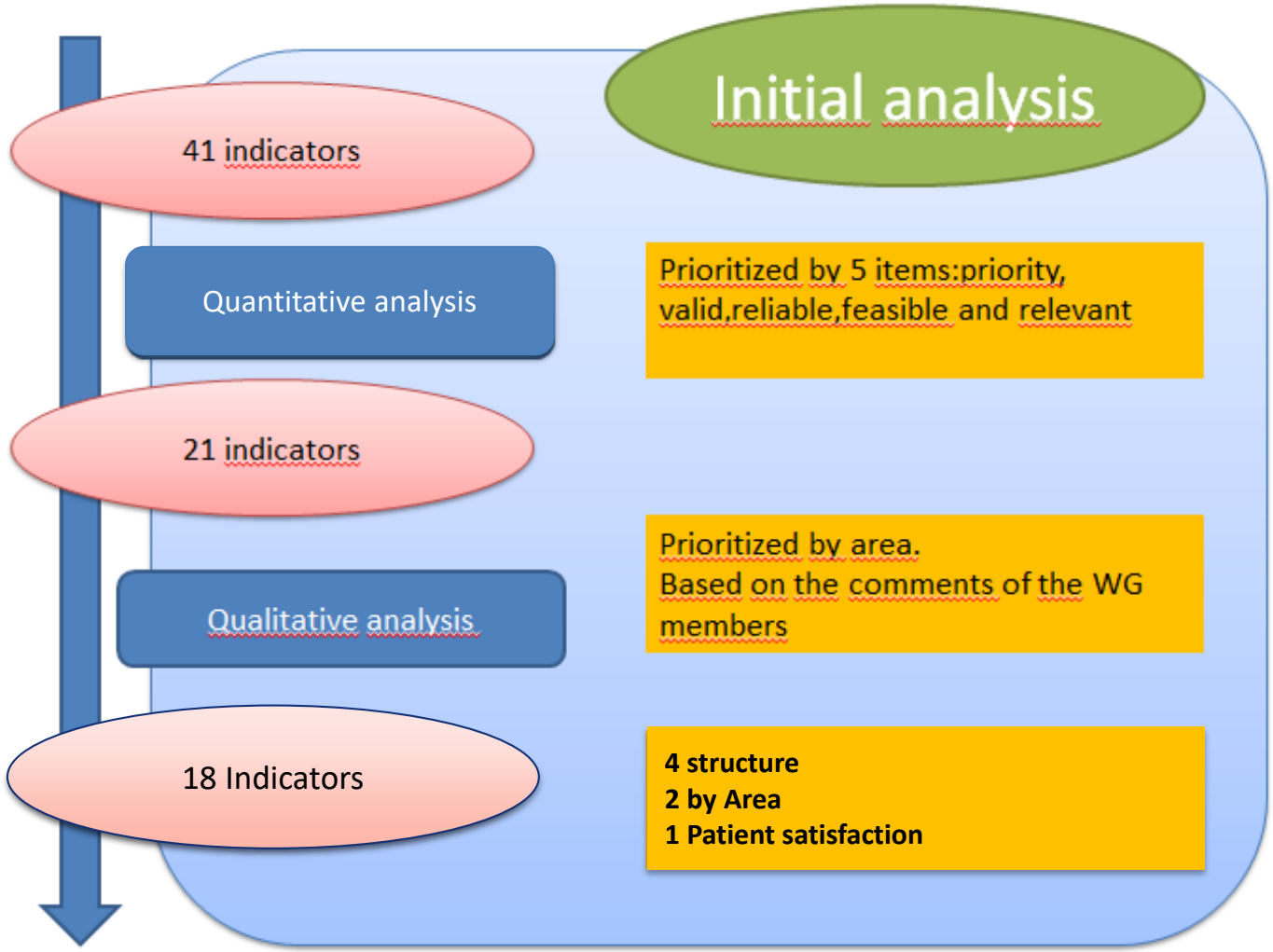
June 18

- Proposal of 18 core indicators applicable to all ERNs

November 18

- Presentation of the initial Monitoring model in the ERN Conference
- Testing of the 18 indicators with real data

Process


Initial analysis
41 indicators
Quantitative analysis
Prioritized by 5 items:priority, valid,reliable,feasible and relevant
21 indicators
Qualitative analysis
Prioritized by area.
Based on the comments of the WG members
18 Indicators
4 structure
2 by Area
1 Patient satisfaction

Scoring

	Objective 2. To improve access to clinical advice, diagnosis, treatment and follow-up of patients within the ERNs						
2.1	Total number of new patients referred to Health Care Providers with diseases/conditions that fall within the scope of the ERN	4.3	4.1	3.5	3.3	4.5	3.9
2.2	Number of patients entered into CPMS (total volume)	4.3	4.3	4.5	4.7	3.6	4.3
	Objective 3. To optimise patient outcomes by combining healthcare professionals' skills & resources used						
3.1	Number of patients entered into CPMS and reviewed by the ERN (a panel case review)	4.6	4.3	4.5	4.8	4.0	4.4
3.3	Delay to provide multidisciplinary clinical advice: Non-emergency cases: average time (days) between referral to ERN and multidisciplinary clinical advice	3.1	3.1	3.7	3.1	3.4	3.3

Auto-generated data from CPMS

	EUROPEAN REFERENCE NETWORK PROJECT STATUS REPORT	Reporting period : JANUARY 2018
	CPMS STATUS REPORT	CPMS, version 2.03 System available since: 20/11/2017

CPMS ACTIVITY

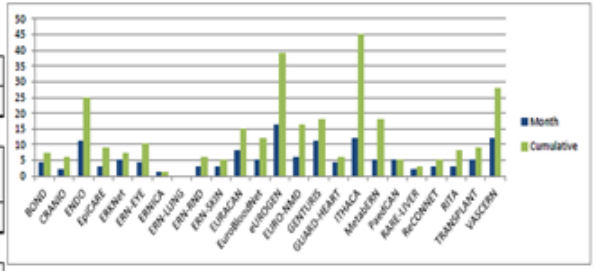
NUMBER OF USERS REGISTERED			
this month	136	Total	598

NUMBER OF ACTIVE USERS (a user who has changed data in the system)			
This month	133	Total	303

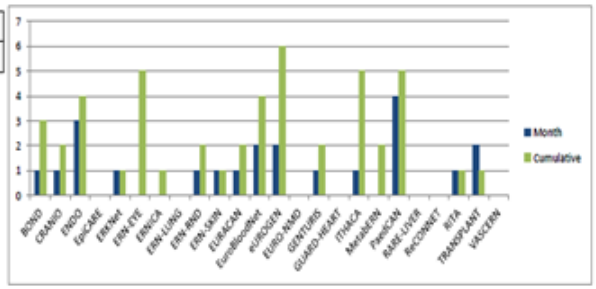
NUMBER OF PANELS			
This month	22	Total	47

NUMBER OF PANELS CLOSED/ARCHIVED			
This month	4	Total	4

ACTIVE USERS/ ERN

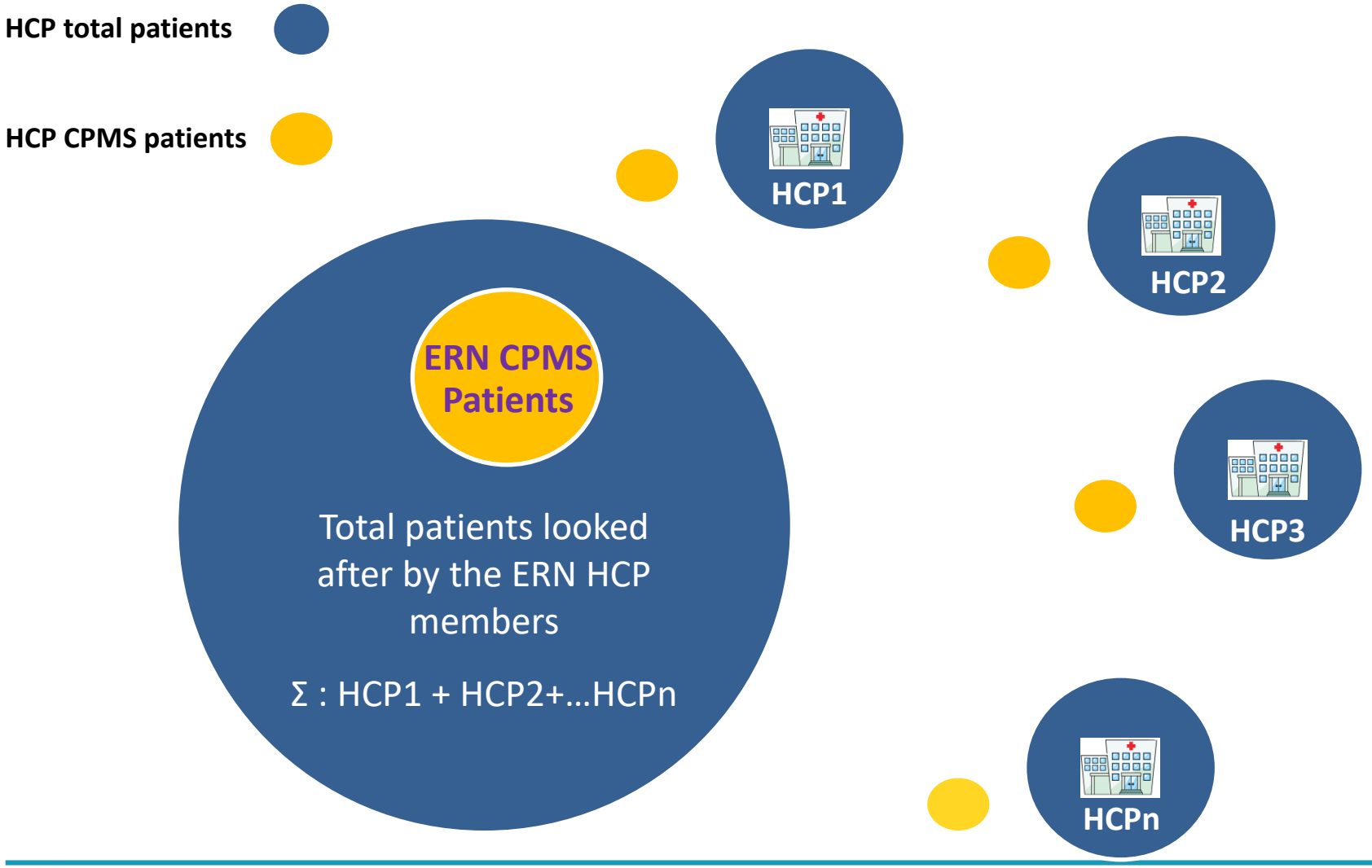


OPEN PANELS /ERN



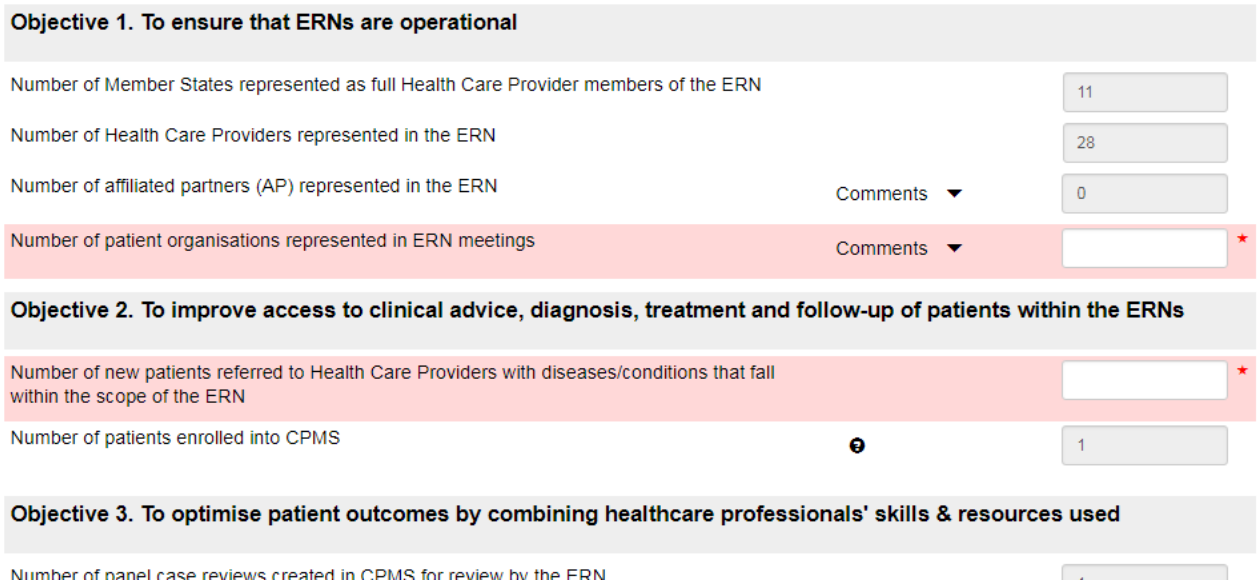
- Number of active users
- Number of patients with panel discussion
- Transfer of knowledge/highly specialised advice

ERN populations



SANTE Data collection

- IT tool to capture data developed
- Piloted by 4 ERNs from Working Group
- Roll out across the ERNs in 2019



Objective 1. To ensure that ERNs are operational

Number of Member States represented as full Health Care Provider members of the ERN		11
Number of Health Care Providers represented in the ERN		28
Number of affiliated partners (AP) represented in the ERN	Comments	0
Number of patient organisations represented in ERN meetings	Comments	*

Objective 2. To improve access to clinical advice, diagnosis, treatment and follow-up of patients within the ERNs

Number of new patients referred to Health Care Providers with diseases/conditions that fall within the scope of the ERN		*
Number of patients enrolled into CPMS		1

Objective 3. To optimise patient outcomes by combining healthcare professionals' skills & resources used

Number of panel case reviews created in CPMS for review by the ERN

External (MS) validation of HCP data and information (indicators applications 2016)

- Stronger involvement of Member States in the assessment of their national HCP
- Focusing in General criteria (Hospital) Specific criteria (activity, etc.)
- Checking criteria of their own healthcare providers
    - when a similar exercise is carried out at national level for other reasons (accreditation or certification of HCP etc.)
    - Ad-hoc

Next steps

Common indicators to all ERNs based on the common objectives of the networks

Indicators specific to each ERN based on technical aspects and disease areas

- Further testing of IT tool for data capture of the common 18 indicators (all ERNs)
- Identify disease specific indicators (under development)
- eUROGEN dashboard presented to ERNs in June 19

Summary

- Data capture on patient numbers and surgical procedures incredibly important
- This data will feed into the IT data collection tool
- Beginning of a process