ERN monitoring and assessment system

3 Dimensions	Main Actors
Continuous <u>monitoring</u> of agreed indicators	**EC, ERN coordinators, BoMs**
Periodical <u>self-assessment</u> and reporting of the ERNs and HCPs;	ERN coordinators with the help of EC
Periodical assessment / validation of specific criteria of the HCP	**Member States**

1.- *Continuous monitoring* *of ERNs activities:*

- Collection of a set of <u>Key Performance Indicators (KPI)</u>
  - ✓ Clinical activity
  - ✓ Networking activities
  - ✓ Knowledge generation, training and research activities

- <u>Outcome indicators</u>

2. *Periodical self-assessment and reporting* *of the ERNs and HCPs;*

- Based on field of expertise and assessment results of each ERN:

✓ <u>specific criteria</u> with lower scores (average of HCP)

✓ Key <u>outcome indicators</u>

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
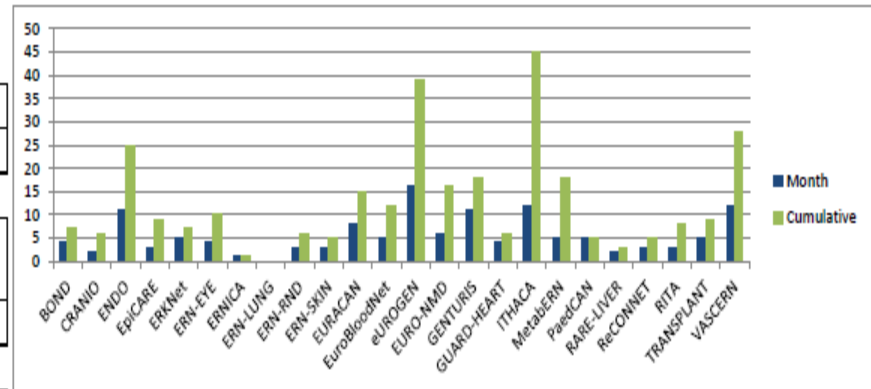
OPEN PANELS /ERN
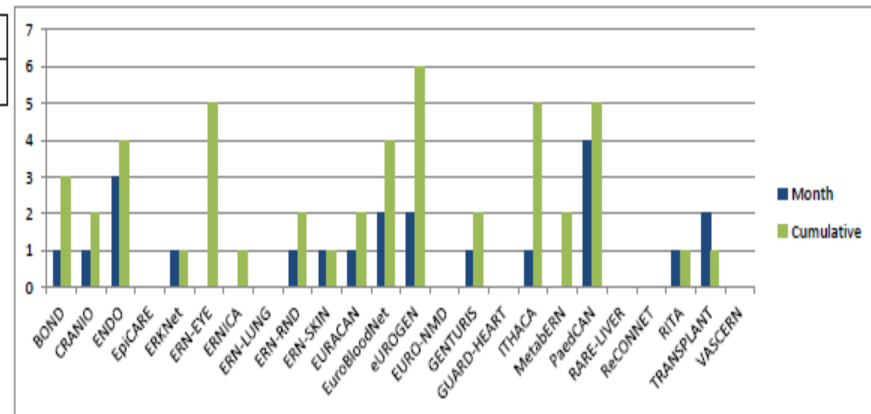
CPMS SUPPORT AND DEVELOPMENT

European Reference Networks | ERN | eUROGEN - Urogenital Diseases

⚕ eUROGEN - Urogenital Diseases USER: Mr. Christopher Chapple

📈 Performance Indicators

Dashboard

Panels

Tasklist

My Meetings

Webinars

Preferences

CO-ORDINATOR

Performance Indicators

ERN meetings

Report name
Active users
Attachments by month
DICOM size breakdown
Meetings by Month
Panels Closed
Panels Created
Webinars by month
Thematic Groups

Apps   ERN CPMS -

ERN | eUROGEN - Urogenital Diseases

eUROGEN - Urogenital Diseases USER: Mr. Christopher Chapple

- Dashboard
- Panels
- Tasklist
- My Meetings
- Webinars
- Preferences

CO-ORDINATOR

- Performance Indicators
- ERN meetings

Reports

	Report type: Active Users

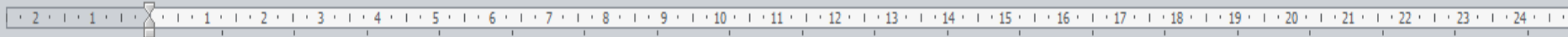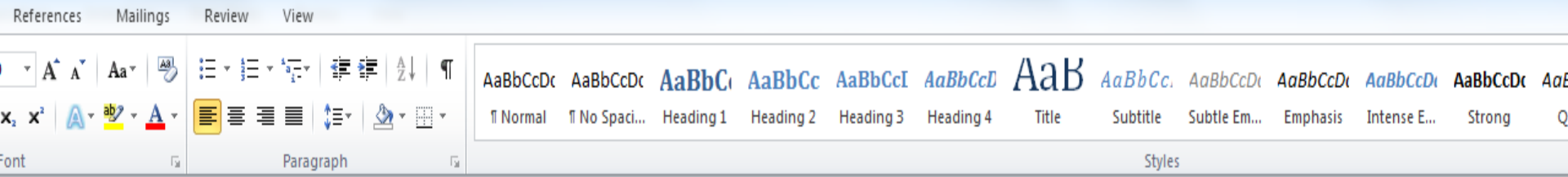| Name	Date joined	Last login
Mrs. Vijay Sangar	16/Nov/2017 10:25 (Europe/London)	07/Mar/2018 08:24 (Europe/Londo
Prof. Wout Feitz	16/Nov/2017 10:26 (Europe/London)	06/Apr/2018 15:08 (Europe/Londor
Dr. Robert de Gier	16/Nov/2017 10:27 (Europe/London)	
Kristina Lisec	16/Nov/2017 10:28 (Europe/London)	
Dr. Jochen Hubertus	16/Nov/2017 10:30 (Europe/London)	01/Mar/2018 18:25 (Europe/Londo
Dr. Marleen Van den Heijkant	16/Nov/2017 10:31 (Europe/London)	
Dr. Maarten Albersen	16/Nov/2017 10:31 (Europe/London)	22/Mar/2018 16:43 (Europe/Londo
Dr. Frank Van der Aa	16/Nov/2017 10:32 (Europe/London)	22/Mar/2018 09:32 (Europe/Londo
Dr. Dirk De Ridder	16/Nov/2017 10:33 (Europe/London)	
Ms. Murielle Ferdinand	16/Nov/2017 10:33 (Europe/London)	

1 to 10 of 60

Stronger external assessment proces_

3. Stronger **involvement of Member States** in the assessment

-   General criteria (Hospital)

-   Specific 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
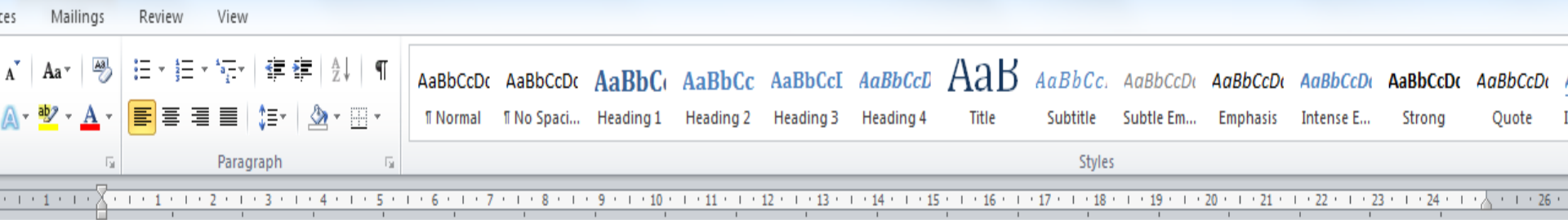
ERN common objective	Indicator name	Indicator type	Responsible for collecting the data	Frequency of data collection
Objective 1. To ensure that ERNs are operational	Number of Member States/European Economic Area (EEA) countries represented in the ERN as full Health Care Providers members of an ERN	Structure	Coordinator	Annually
	Number of Health Care Providers represented in ERN	Structure	Coordinator	Annually
	Number of affiliated partners represented in the ERN	Structure	Coordinator	Annually
	Number of patient organisations represented in the ERN meetings[1]	Structure	Coordinator	Annually
	% of Member States/EEAs within the ERN, formally designated a leading role (Chair) in a disease area/thematic working group	Process	Coordinator	Annually
	Number of Member States/EEAs represented by patient organisations as part of the ERN	Process	Disease Area/Thematic Group/coordinators or leaders to Coordinator	Annually
	% of Member States/EEAs represented by patient organisations as a part of the ERN	Process		
	Number of disease-specific/thematic working groups with patient	Structure	Disease Area Coordinators/leaders to	Annually

ERN common objective	Indicator name	Indicator type	Responsible for collecting the data	Frequency of data collection
Objective 2. To improve access to clinical advice, diagnosis, treatment and follow-up of patients within the ERNs	Total number of new patients referred to Health Care Providers with diseases/conditions that fall within the scope of the ERN [2]	Outcome	Coordinator	Annually
	Number of patients entered into CPMS (total volume)	Process	Coordinator	Annually
Objective 3. To optimise patient outcomes by combining skills of healthcare professionals involved and resources used	Number of patients entered into CPMS and reviewed by the ERN (a panel case review)	Process	Coordinator	Annually
	Emergency cases: average time (days) between referral[3] to ERN and multidisciplinary clinical advice[4]	Process	Coordinator	Annually
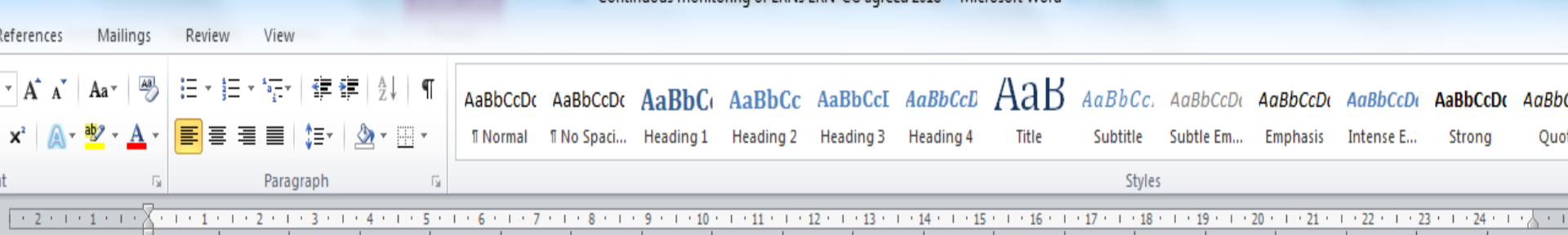
Non-emergency cases: average time (days) between referral[5] to ERN and multidisciplinary clinical advice[6]	Process	Coordinator	Annually
Emergency cases: Treating clinician satisfaction[7] with CPMS outcome	Outcome	Network Coordinator	Annually
Emergency cases: Treating clinician compliance[8] with CPMS outcome	Outcome	Network Coordinator	Annually
Non-emergency cases: Treating clinician satisfaction[9] with CPMS outcome	Outcome	Network Coordinator	Annually
Non-emergency cases: Treating clinician compliance[10] with CPMS outcome	Outcome	Network Coordinator	Annually
Number of disease-specific indicators for evaluation of the ERN[11]	Process	Network Coordinator	Annually

Two Dimensions

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

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

(2) Disease Specific Clinical Outcomes

ERN Continuous Monitoring System outlines the requirements for each ERN to:

***Self-define disease specific clinical outcomes** per each disease area or intervention for evaluation of the ERN*

Each disease specific working group or sub-thematic area should be working to identify a small number of key clinical outcome measures specific to the disease area.

*Indicators/measures should be **profiled against the case mix**.*

*Be **reviewed annually** to promote discussion and learning between HCPs and identify areas of emerging best practice and new innovation.*

Key challenges

- Data collection

Source of the data		Registration of the data		Reporting
Source of the data *Availability, quality, burden of measurements*	→	**Registration of the data** How to collect the data	→	**Reporting** How to use the data

- Definitions and methodological issues

Next steps

1. *Brainstorming and integration of the views of the WG of the ERN –CG with the WG of the ERN Board*

2. *Analysis of resources and capacity to develop the info system (sources, IT solutions)*

3. *Further discussion on the set of indicators proposed by the ERNs with the WG BoMS*

   o Priorities (Core and extended set of indicators)
   o Methodology: Definitions, Indicators numerator/denominator
   o Discussion on the feasibility, utility and appropriateness
   o Identification of the sources of information
   o Software/database/analysis/ balanced scoreboard etc.

Next steps

1. *Further discussion on the set of indicators proposed by the ERNs with the WG BoMS*

Both WG will , as preparatory work for the meetings, provide their inputs on the proposed set of indicators on:

- o Level of priority (Core and extended set of indicators)
- o Feasibility, utility and appropriateness of each of the indicators
- o The leads of both WG will use a common adapted format of the current list of indicators for collecting this information.

2. *Analysis of the IT dimension by DG SANTE Software/database/analysis/ balanced scoreboard etc.*

3. *Both WG will complete and agreed on the methodology and indicators elements pending: Definitions, Indicators numerator/denominator*
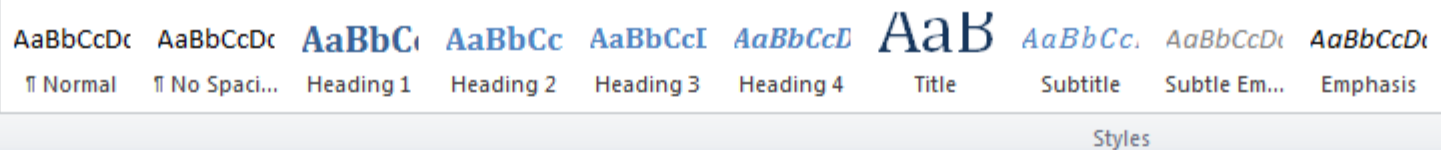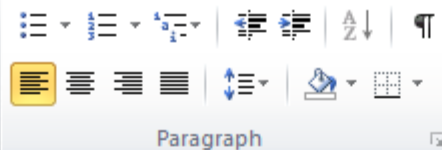
Timing: meetings

✓ **<u>Preparatory work (April):</u>** *Internal work / WebEx / TC of each of the WG April: organized by leads of the WG. SANTE will provide the WebEx call at request:*

✓ **<u>1st meeting of both WG (May beginning).</u>** *WebEx Doodle for the date (Organized by SANTE).*

✓ **<u>BOMS WebEx on involvement of MS in the assessment (2sd half May)</u>** *. To decide format and date*

✓ **ERN CG and BoMS June:** *Presentation, discussion & eventual agreement on the next steps of the Monitoring system.*

Other pending issues to be adressed

✓ *Participants in the Common WG on Monitoring*

✓ *Patient Satisfaction Survey*

Indicator name	Examples of questions to be discussed
evel of patient satisfaction	Patient satisfaction (of patients who have been entered in CPMS, had a panel review discussion ar report has been produced) could be measured using the Rare Barometer Voices, which is a tool us quantitative surveys on issues affecting people living with a rare disease. The Rare Barometer Voi high-quality, secure data collection and analysis. It is recommended that as a first step, adults are questions: • Did you give your consent for your data to be shared for: the Clinical Patient Management Syste (Yes or No). • How satisfied were you with the information given to you about the ERN? (Not satisfied; Quite s • Was the outcome report giving the ERN advice or recommendations shared with you? Yes or No • How satisfied are you with the ERN advice or recommendations? (Not satisfied; Quite satisfied; • How satisfied are you that your treating clinician involved you in discussions about how the ERN (Not satisfied; Quite satisfied; Very satisfied) • Do you have any comments or suggestions about the activities of the ERN? The process of the measurement of patient satisfaction needs to be defined as an integrated proc The adult patient, and in case of children, parents should complete the question outside the hospi provision of information of where and how to complete the online-survey, by the clinician. Fundin any necessary adaptations to the Rare Barometer Voices and to translate the questions into differ Comment: The assessment is not regarded as research and therefore not considered to need the s proposed first step. Research with regard to measurement of patient satisfaction would require d such as a robust and patient-centred methodology of the development and validation of a cross-c