



Co-funded by
the Health Programme
of the European Union

EUROPLAN Debrief Sessions:

Identifying strengths and areas for support and development

Amalia Egle GENTILE

EUROPLAN 2012-2015 Coordinating Team

*Italian National Centre for Rare Diseases
Italian Institute of Health
Rome, Italy*

Victoria HEDLEY

EUCERD Joint Action Team

*MRC Neuromuscular Centre at Newcastle
Institute of Genetic Medicine - Newcastle University
Newcastle upon Tyne, United Kingdom*

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

8 May 2014 - Federal Ministry of Health, Berlin

EUROPLAN Debrief Sessions





A specific post-National Conference activity

For approximately 1 hour or 1 ½ hour,
at the end of the EUROPLAN NCs



In each MS
where a EURORDIS will organize a NC,
starting from February 2013



...and Serbia





- 1/2 MoH representatives plus key persons involved in elaboration/implementation of NP
- 1/2 EUROPLAN Coordinating Team member/s
- 1 EJA Coordination representative
- 1 EURORDIS Advisor

- To collect data, analyse the national situation and explore priorities in order to provide scientific and technical support to the MS.
- To establish and build a dialogue between MS NP/NS teams and the EUROPLAN/EJA colleagues
- What Debrief Sessions are *not*





A DS at the end of the EUROPLAN NCs

A dedicated support proposal agreed among ISS, EURORDIS and UNEW

Proposal shared with the DS participants and sent to the MoH, in order to plan and develop a specific pathway to support them

The MoH should identify the specific proposals they wish to implement



A common format

Standard Operating Procedures

Examples of Proposals

- Maximising the expertise available to the teams, to promote the sharing of good practices between MS, exchange the latest outputs, and facilitate discussions between national stakeholders
- Exchanging information - sharing the latest progress on our dedicated WPs for CEs, Coding, Specialised social services, genetic testing etc.
- Organising workshops dedicated to several key themes, involving DS participants, and trying to promote opportunities for countries to discuss key issues with those facing similar challenges
- Providing practical hands-on support, with issues such as establishing helplines
- Aim - these proposals of support compliment the activities being explored for building capacity across the MS

EMERGING RESULTS

- DS to date seem to identify the following as priority areas for which additional support could be beneficial:



- However, there are many thematic priorities emerging, necessary to build a comprehensive RD policy framework - and many examples of good practices from MS to MS

1. **Slovak Republic** (Bratislava, 28 February 2013)
2. **Romania** (Bucharest, 24-25 May 2013)
3. **Finland** (Helsinki, 21 September 2013)
4. **Poland** (Warsaw, 28 September 2013)
5. **Hungary** (Budapest, 25 October 2013)
6. **Lithuania** (Vilnius, 14 November 2013)
7. **Cyprus** (Nicosia, 15 November 2013)
8. **Luxembourg** (Luxembourg, 20 November 2013)
9. **Serbia** (Belgrade, 7 December 2013)
10. **Italy** (Rome, 28 January 2014)
11. **Croatia** (Zagreb, 28 February 2014)
12. **Belgium** (Brussels, 28 February 2014)

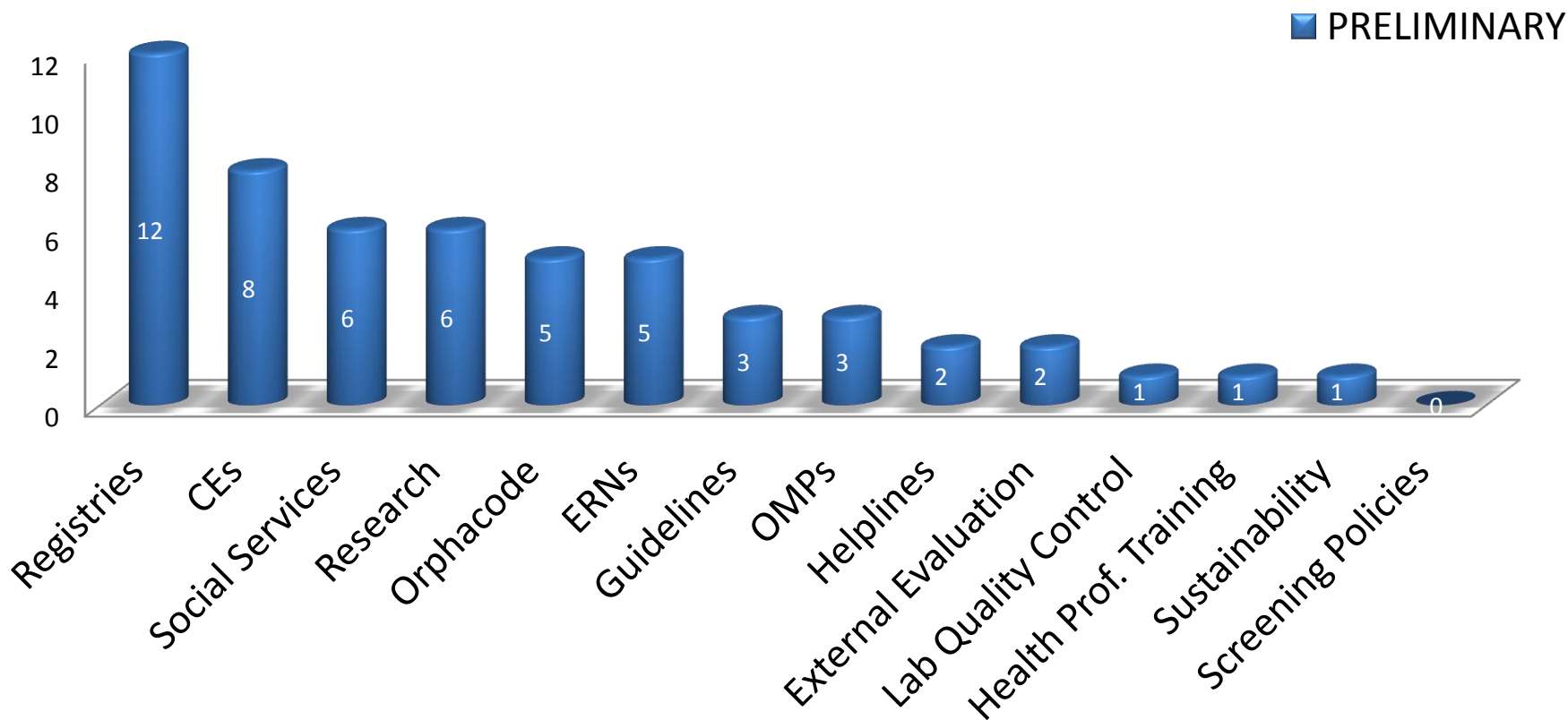
DEBRIEF SESSIONS

UP TO DATE



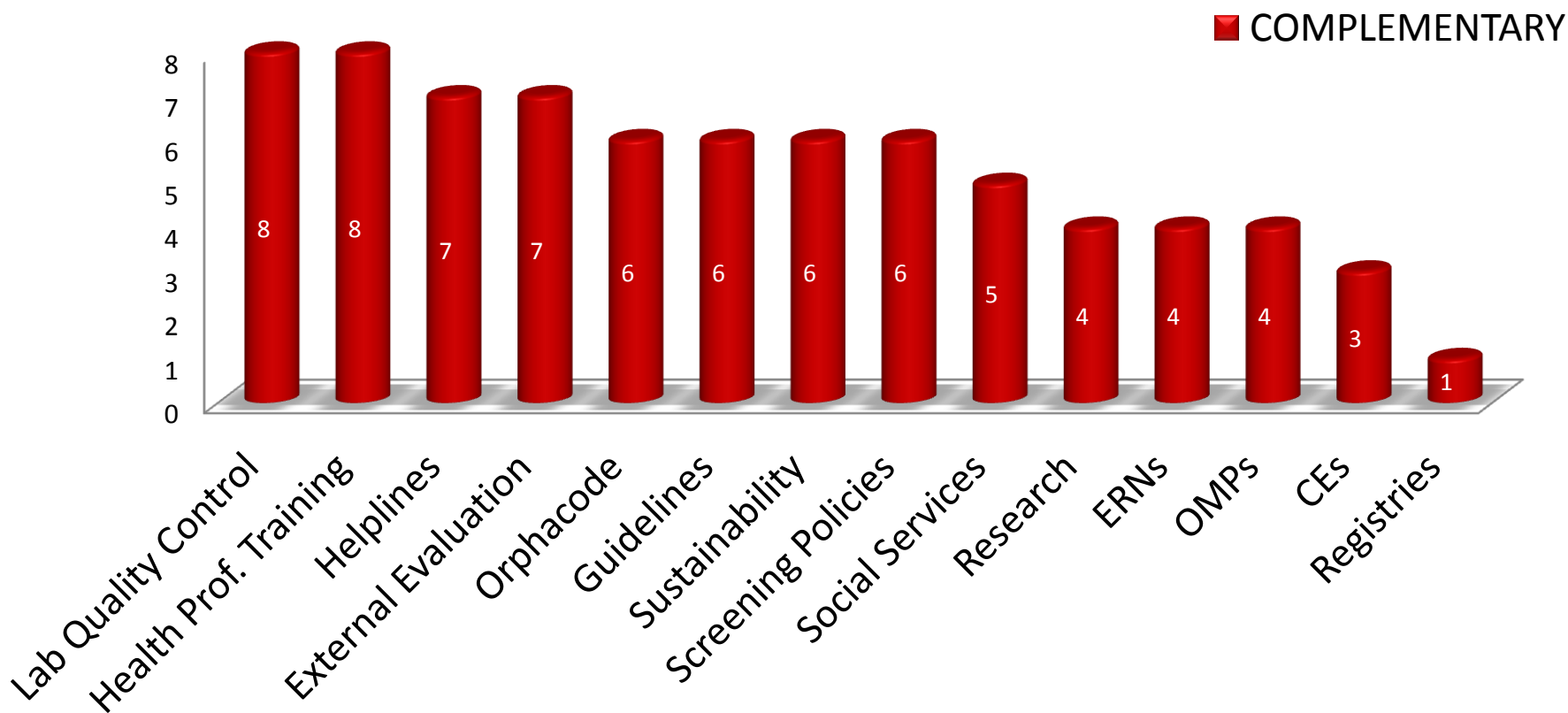


EXPRESSED NEEDS



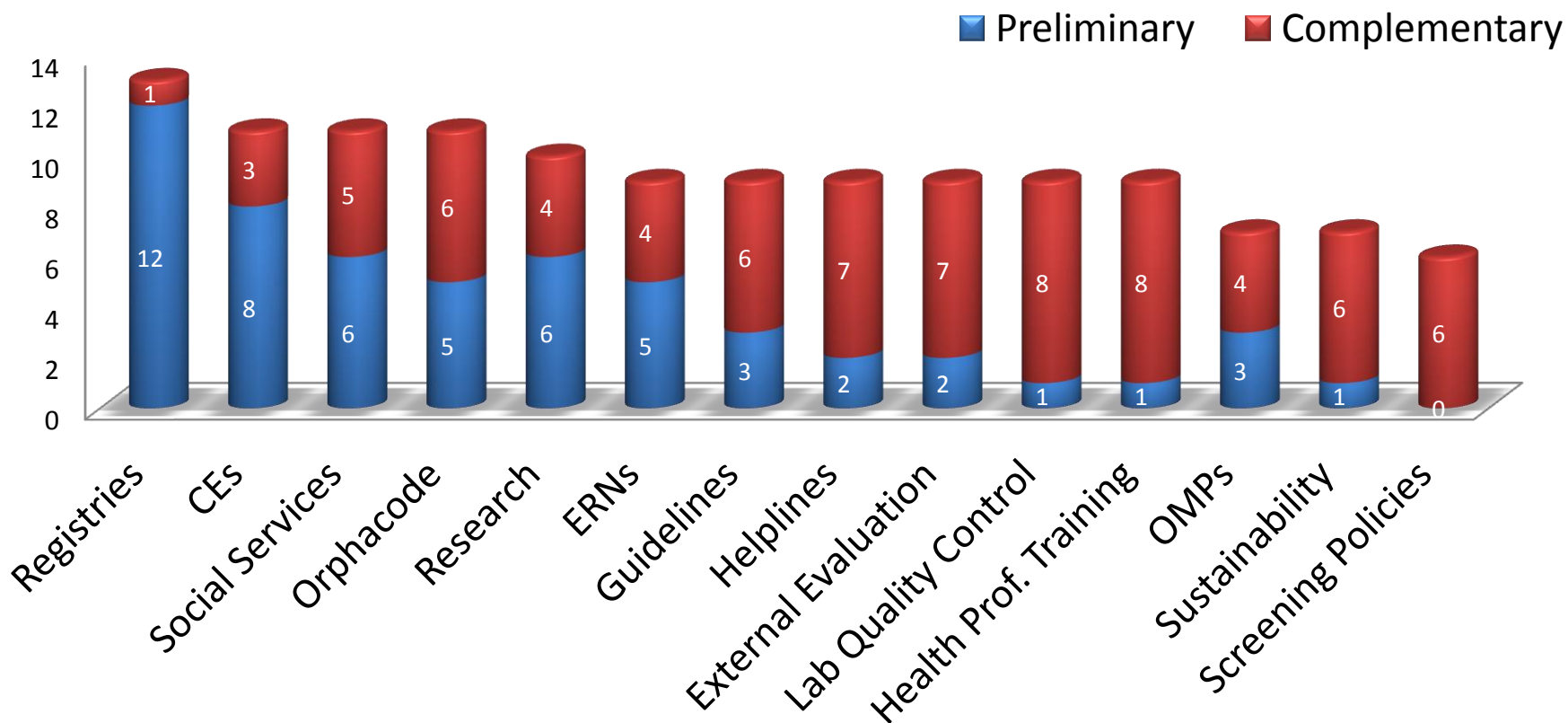


EXPRESSED NEEDS





EXPRESSED NEEDS



...this is **FIRST STEP** of the
CAPACITY BUILDING PROCESS



Capacity building

Increasing the *quality* and *quantity* of work that an individual/organisation is able to do



An on-going evidence driven process of strengthening the abilities of individuals, organizations, and/or systems to perform core functions sustainably, and to continue to improve and develop over time.

...like building blocks...

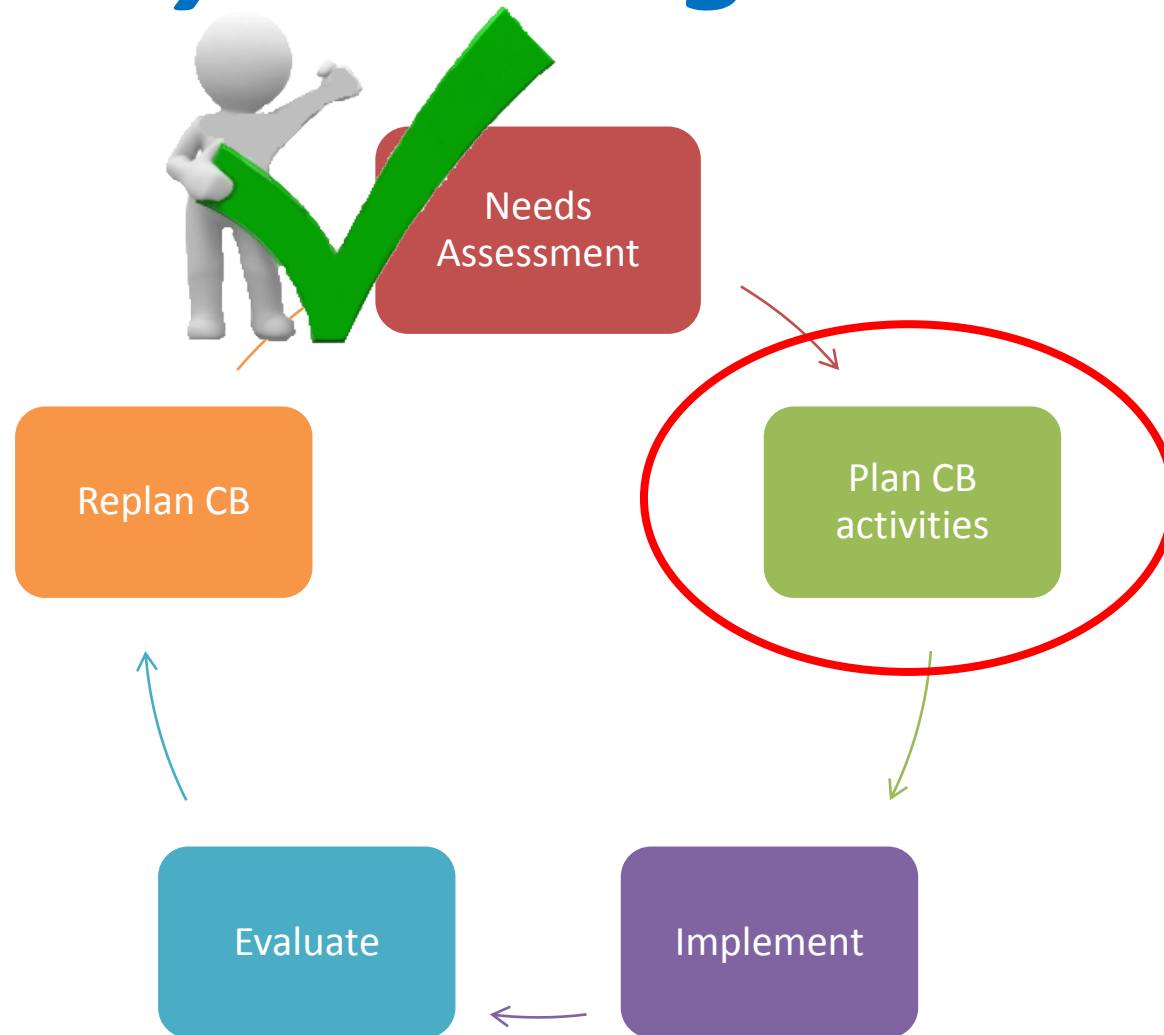
in the sense that capacity is built block by block...
and each block consists of a different component.



Capacity building starts with the expression of needs and their assessment



Capacity building *PROCESS*





ACTIVITIES & modalities

Training

Technical support

Peer-to-peer support

Linking to networks

Supervision

Monitoring

Evaluation

Quality Assessment

Providing information

Other...

Face-to-face

On the job

Learn by doing

e-learning

Webinar

Distance support

Teleconference

Working Groups



To TRANSLATE MS NEEDS
into a
CAPACITY BUILDING OPERATIONAL PLAN



- TUNING UP the expressed needs through the identification of activities and modalities
- PRIORITISING these activities and modalities.

Working Groups



4 thematic areas
Groups

Registries
and Coding

CEs and
ERNs

Research

Social
Services
and
Guidelines



Working Groups

Phase I (individual) – 20 minutes

Each participant fills in the questionnaire **TO TUNE UP THE EXPRESSED NEEDS + ACTIVITIES AND MODALITIES**

Break 10 minutes

Phase II (small groups) – 90 minutes

Participants are divided in 4 thematic groups

Each group elaborates an agreed proposal of support, **TO PRIORITISE THESE ACTIVITIES AND MODALITIES**

Facilitators: EUROPLAN Staff

Rapporteurs: EURORDIS and UNEW Staff

Phase III (plenary)

Each rapporteur presents the small group conclusions (5 min. per group).

All participants discuss and agree the proposals.



Working Groups

COMPOSITION

Registries and Coding

- Ursula UNTERBERGER (AT-HealthInst.)
- Pilar SOLER CRESPO (ES-MoH)
- Svetlana KARIMOVA and Albina MAKAEVA (RU-EUROPLAN Partner)
- Dragan VUKANIĆ (RS-MoH)
- Francis AGIUS (MT-MoH)
- Ali FARHANA (UK-EURORDIS)

Research

- Zane STRAUME (LV-Uni/MoH)
- Maria Elena CONGIU (IT-MoH)
- Tatiana FOLTANOVA (SK-Uni/MoH)
- Liam McCORMACK (IE-MoH)
- Hugh DAWKINS (AU-DepHealth)
- Lene JENSEN (DK-EURORDIS)

CEs and ERNs

- Eva MURKO (SI-MoH)
- Anzelika BALCIUNIENE (LT-MoH)
- Saskia VAN DEN BOGAERT (BE-FedPub)
- Emilia SEVERIN (RO-MoH)
- Paul BOOM (NL-MoH)
- Simona BELLAGAMBI (IT-EURORDIS)

Social Services and Guidelines

- Véronique HÉON-KLIN (DE-MoH)
- Ingeborg BARISIC (HR-Uni/MoH)
- Inna VABAMAE (ES-Min.Social Aff)
- Katalin BRUNNER (HU-RDNP Comm)
- Bengt RÖNNGREN (SE-Min.Health and SocialCare)
- Oleg KVLIVIDZE (GE-EURORDIS)