



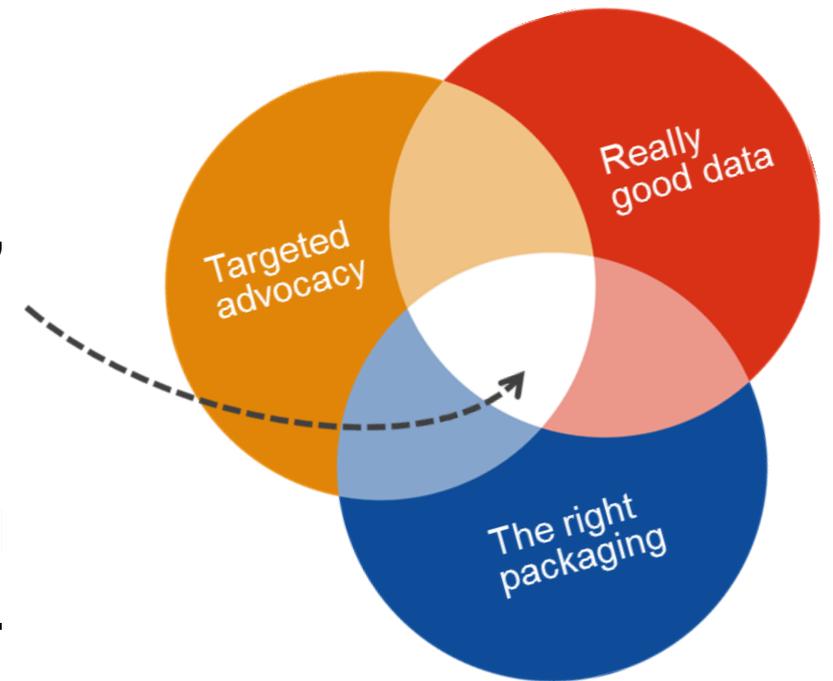
WECAN Capacity Building Course on Evidence-Based Advocacy: Generation and Publication

compiled by Jan Geissler, Tamás Bereczky, Zack Pemberton-Whiteley

Evidence-based advocacy – What is it?

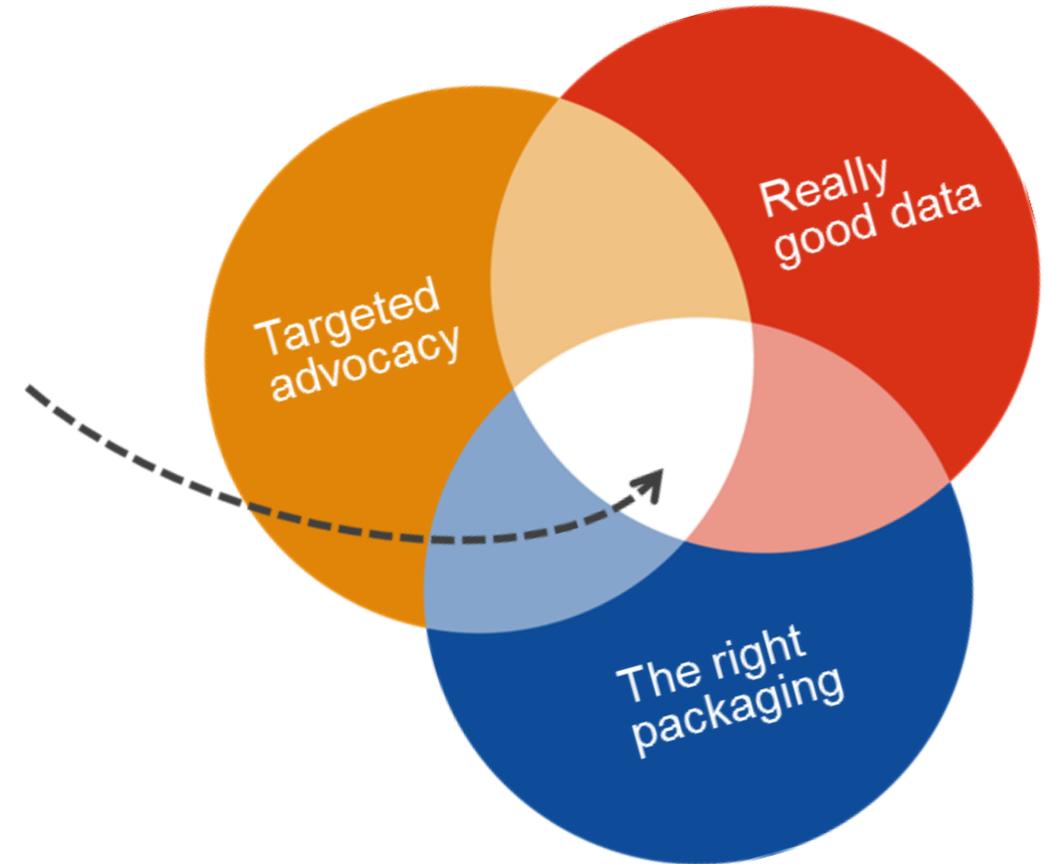
Systematic and targeted collection, interpretation, generation and deployment of sound data and information, presented and used in patient advocacy with an objective in mind.

Advocating in a targeted, evidence-based, well-educated and professional manner, and measure impact and outcomes of what we do.

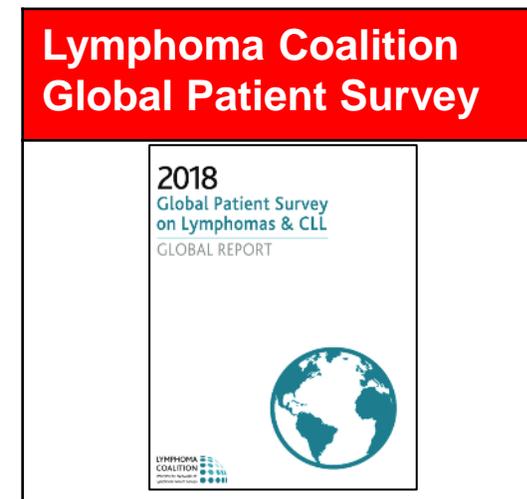
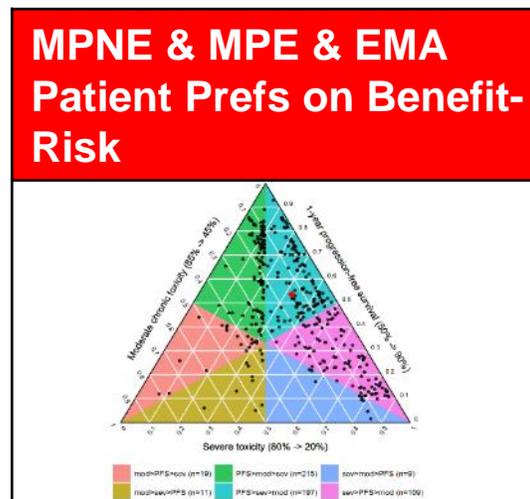
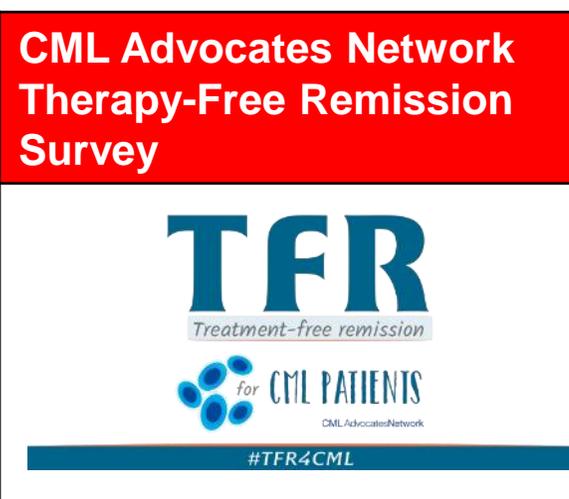
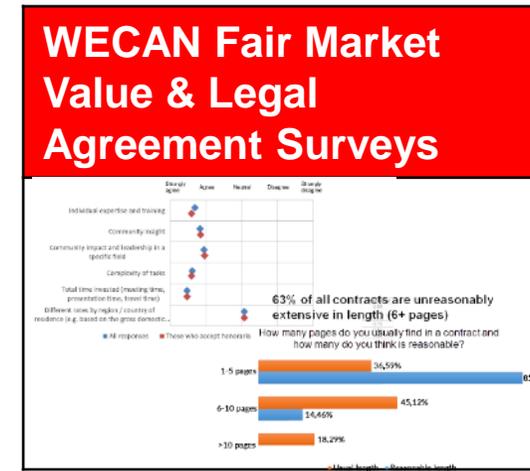
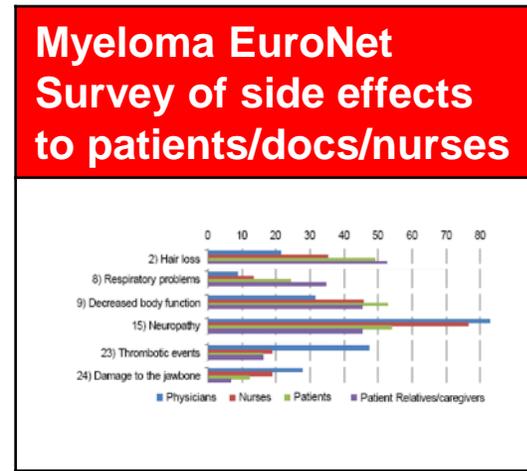
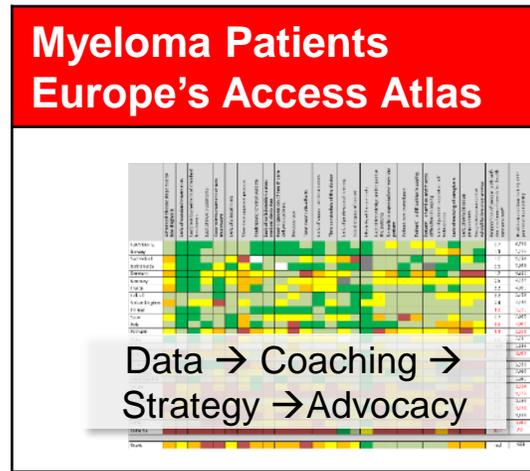
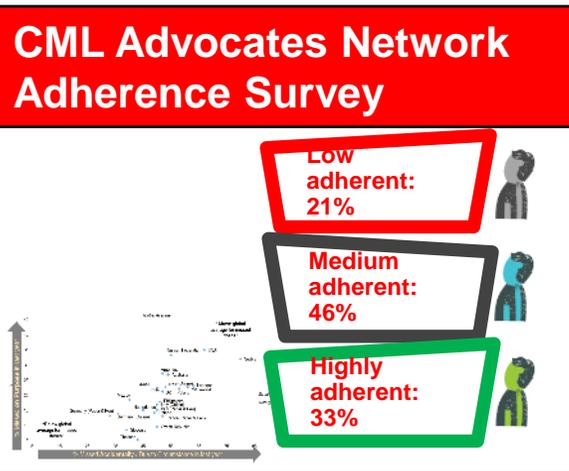


Meaningful data that patient groups can generate

- **Adherence** to therapies
- **Inequalities in real-world access** to diagnostics or therapies
- **Current care patterns**
- **Quality of Life, burden of disease, daily lived experience** in real world
- **Impact of illness** on society
- **Disease-related outcomes**
- **Patient preferences on benefit/risk**



Great examples of evidence generation in the WECAN community



- ### ...and many more community examples
- EuropaUomo
 - MPNE
 - Digestive Cancers Europe
 - INCA
 - ...

Challenges of patient organisations to generate data for advocacy

- Numerous presentations (e.g. IKCC, MPE, MPNE, MPE, WECAN Academy) about evidence-based advocacy have strongly increased awareness and importance of evidence-based advocacy in our community
- However, only a small number of patient organisations have
 - the **knowledge how to generate data** in a methodologically sound way
 - the capacity to **implement** an evidence generation project
 - the knowledge how to **use the data** in advocacy
 - knowledge, capability and resource to **publish the data**
 - a **strategy** to ensure generation of data not only when invited/encouraged by industry



WECAN “Evidence-Based Advocacy Training Program: Generation and Publication”



Run a specialist education program on “Evidence-Based Advocacy: Generation and Publication”

Objectives:

- Empower WECAN members on evidence generation and publication
- Provide training and coaching for one person in each of the WECAN members to act as evidence-generation lead
- Align with WECAN publications course being developed in partnership with Envision

Implementation:

- Develop and run capacity building course for 1 representative of each of the 22 WECAN members on evidence-based advocacy – generation and publication
- Provide follow-up coaching for a specific project, up to 10 hours per WECAN member organisation

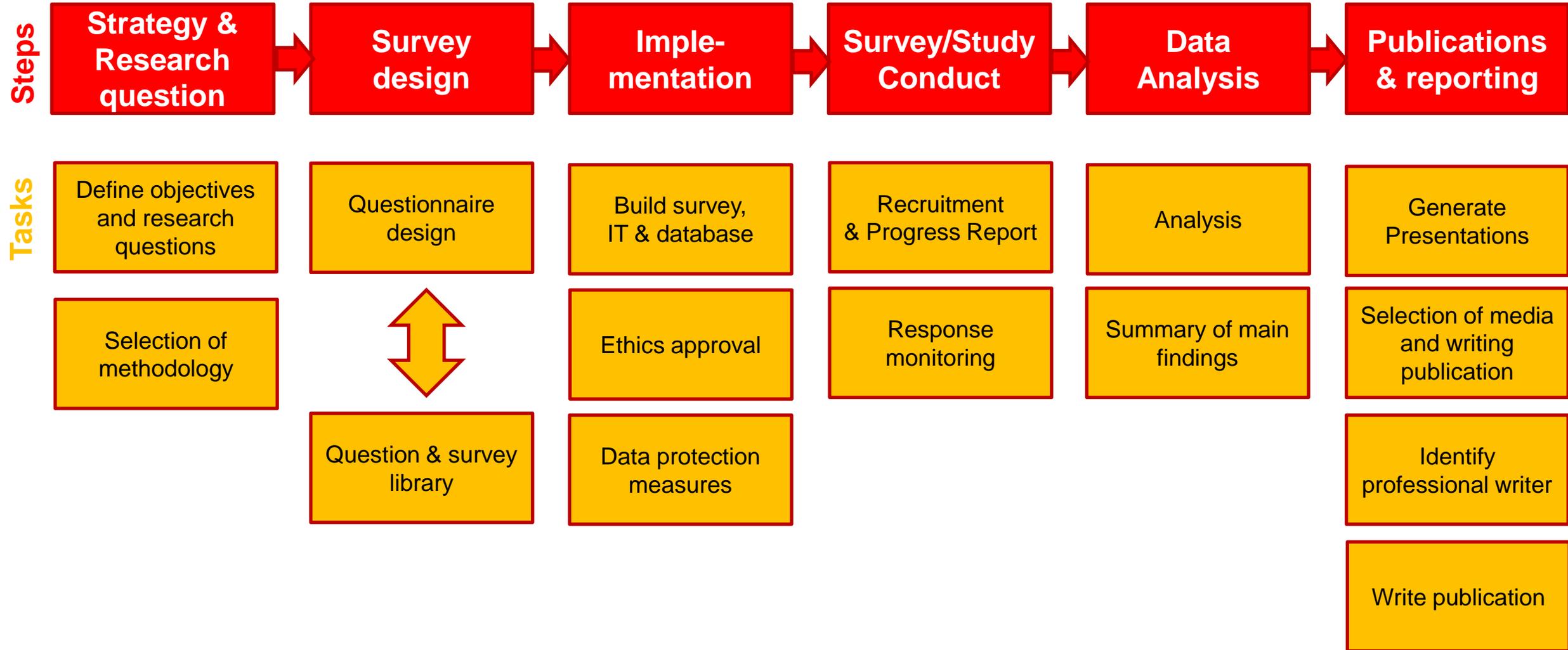
Timeline

- March 2020 to March 2021

Learning Objectives of the Course

1. Understood what **evidence-based advocacy** is
2. Learned from **examples** we already have, and the challenges they experienced
3. Developed **methodological knowledge** how to implement evidence based advocacy
4. Understood the **publishing process** and know how to publish data of patient-led research, or be involved in the publication or review of clinician-led research
5. Received **coaching on developing a strategy** for evidence-based advocacy in their WECAN member organisation
6. Developed a **concrete project idea** on evidence-based advocacy in their WECAN member organisation

Evidence Generation for Evidence-Based Advocacy: Key elements of the Capacity Building Course



Planned Timelines - Draft



Course month	Course content
January – March 2020	Content Development
March 2020	Project kick-off
April 2020	Start of recruitment of trainees through WECAN members
April 2020 - w/c 27	Pre-Course Survey of Trainees
May 2020 - w/c 4 or 11	Teleconference with trainees: Online kick-off of the programme
May 2020 - w/c 4 or 11	Webinar 1: Introduction to evidence-based advocacy and policy
May 2020 - w/c 18 or 25	Webinar 2: Overall process of evidence generation and publication and all steps involved.
June 2020	Webinar 3: Strategic Planning: setting overall priorities and objectives of the research
July 2020	Webinar 4: Research question and project planning: Define objectives and research questions & selecting a methodology
August 2020	Webinar 5: Questionnaire design, with potential use of existing questionnaires and survey libraries
September 2020	Webinar 6: Implementation: Build survey, IT and database, ethics approval & data protection measures
October 2020	Webinar 7: Conduct: Recruitment of participants, monitoring, progress reporting
November 2020 - w/c 2 or 9	Webinar 8: Analysis: Analysis & summary of main findings, internal presentation of results
November 2020 - w/c 16 or 23	Webinar 9: Publication of evidence: Generating publications and presentations, selecting media and writing publication, identifying professional writer, identifying target journals, writing publications, submission process
January 2021 - TBC	Face-to-face training meeting of all 22 trainees – Putting the Theory into Practice
January - March 2021	Individual coaching of patient organisations on developing project plans (10 hours per organisation, maximum 22 WECAN organisations)
March 2021	Follow-up virtual meeting to discuss advocacy work plans and share best practice between WECAN member organisations