

Fostering continuous quality improvement in a European rare disease network



Olivia Spivack (Implementation coordinator/researcher)

The **E**uropean **R**eference **N**etwork for rare **I**nherited **C**ongenital **A**nomalies (ERNICA)

High-quality healthcare

"Doing the right **thing**, at the right **time**, in the right **way**, for the right **person** and having the **best possible results**"

Agency for Healthcare Research & Quality



The rare disease challenge

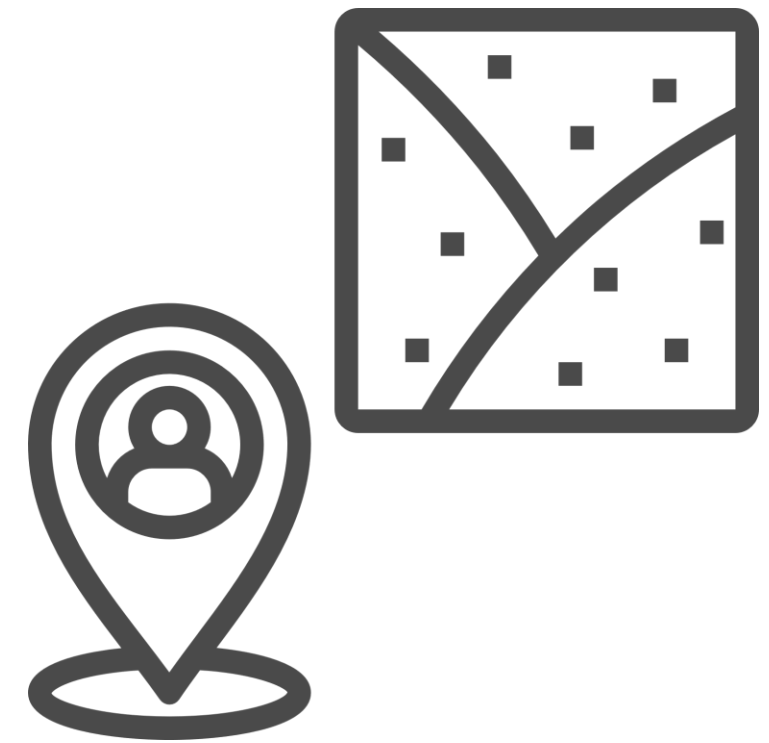


What does high quality care look like?



How can it be achieved?

The rare disease challenge




The European Reference Networks (ERNs)

Cross-border collaboration & the pooling of expertise and knowledge



**European
Reference
Network**

for rare or low prevalence
complex diseases

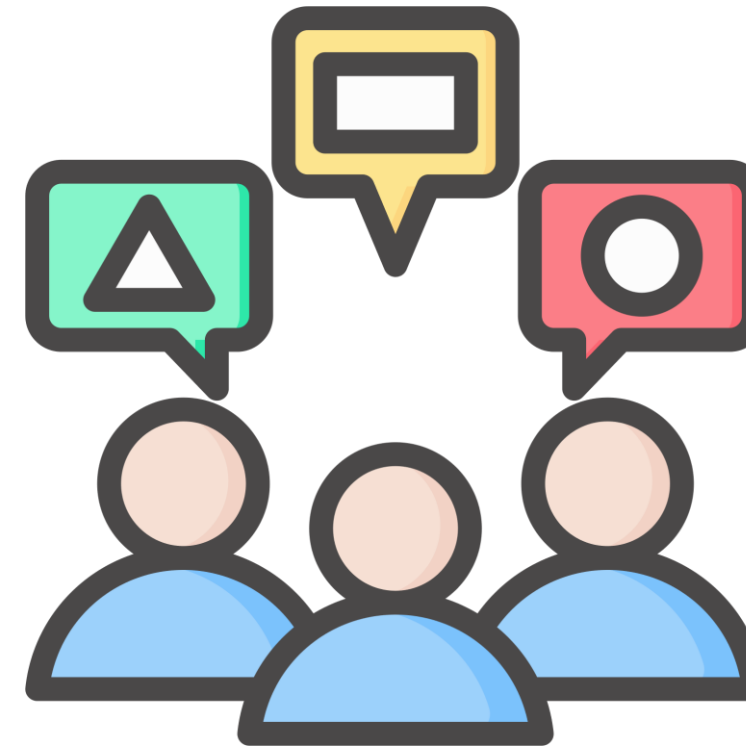
 **Network**
Inherited and Congenital
Anomalies (ERNICA)



The European Reference Networks (ERNs)



Context heterogeneity



Hospital variation

Undesired practice variation?

Challenge to define what 'high quality care' looks like and
how it can be achieved for our patients...

&

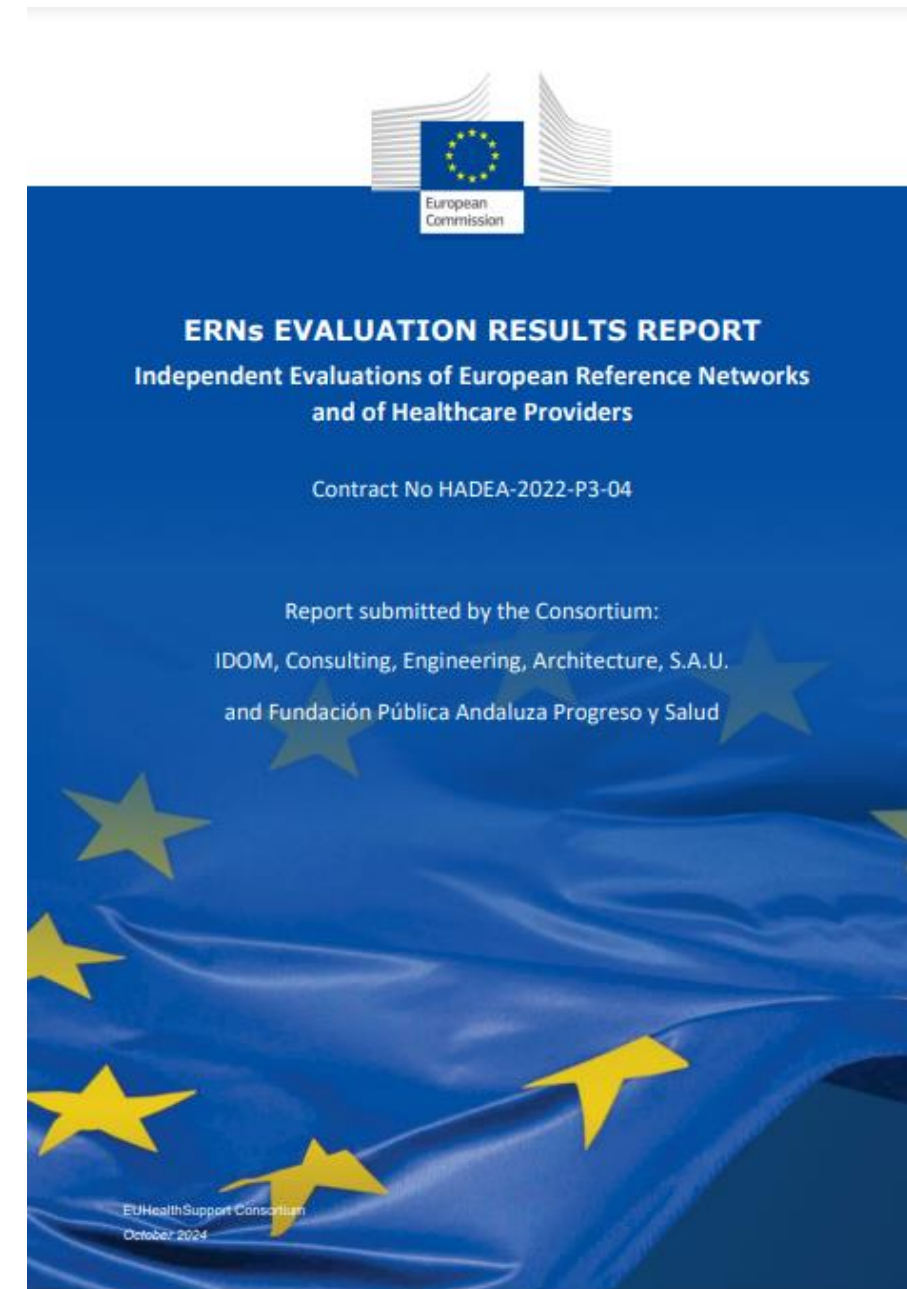
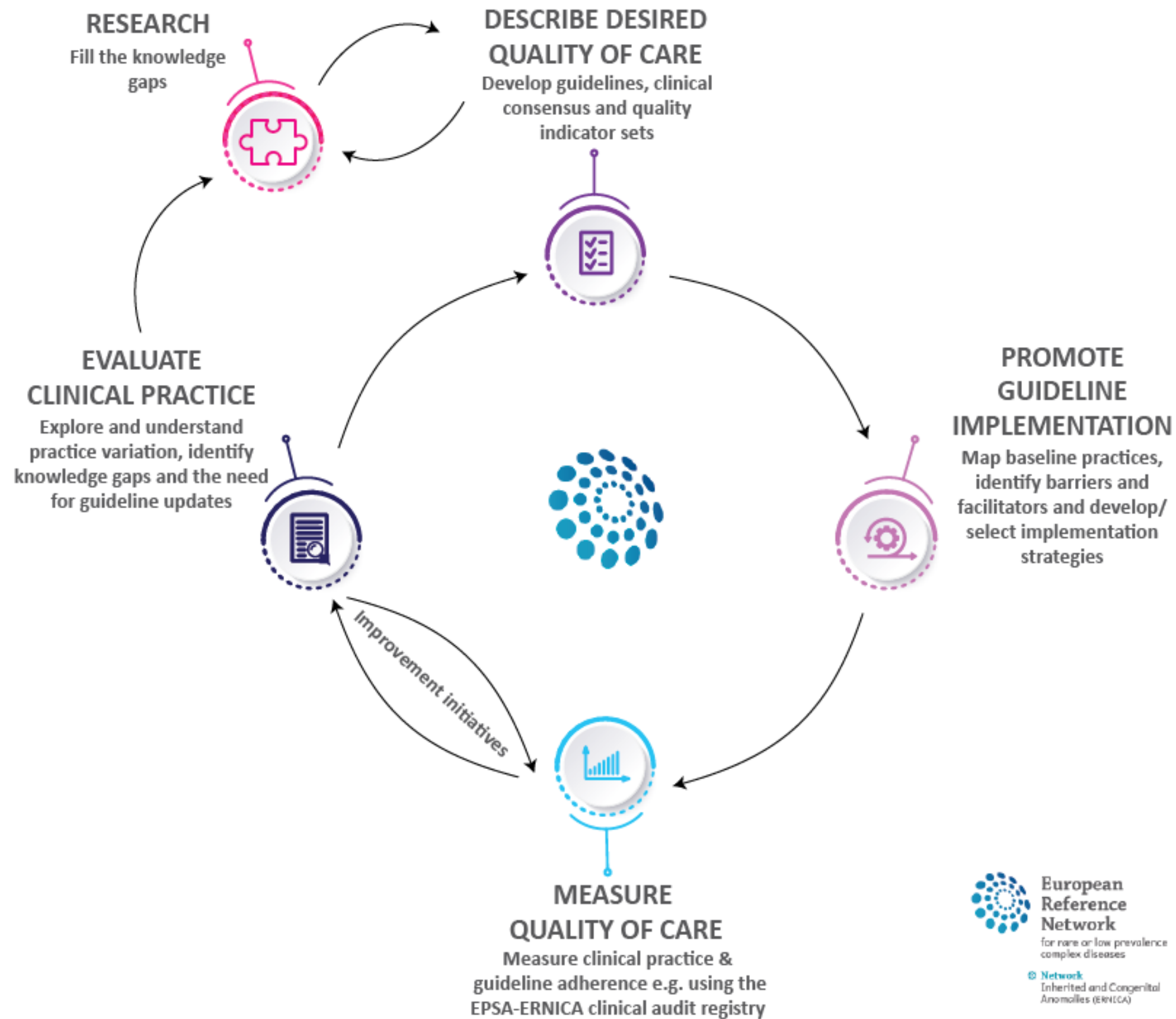
Risk of undesired practice variation across Europe...

=

the ERNICA Quality Cycle

An iterative, quality improvement framework

The ERNICA quality cycle



(1)

Describing the desired level of care



Clinical practice guidelines



**Formal clinical consensus using a
structured Delphi approach**

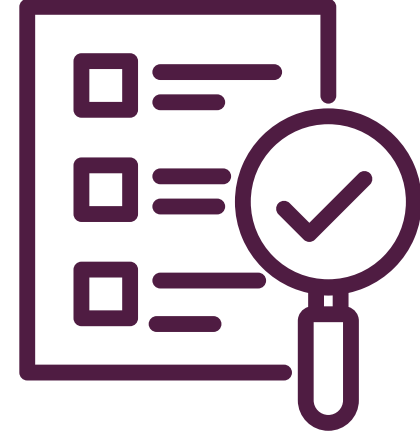


**Innovative methodological strategies to
support guideline development**

E.g. Use of 'real world' clinical audit data, the use of 'indirect' evidence, n=1 trials, expert opinion solicited through structured observation forms

(1)

Describing the desired level of care



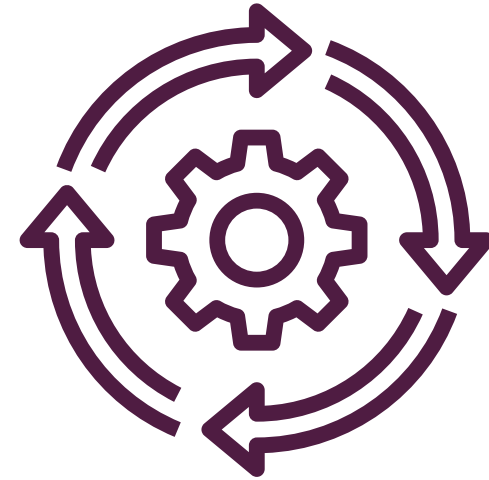
**Quality indicator development
(Structural, process, outcome)**



**Standardised definitions (of diseases,
treatments..)**

(2)

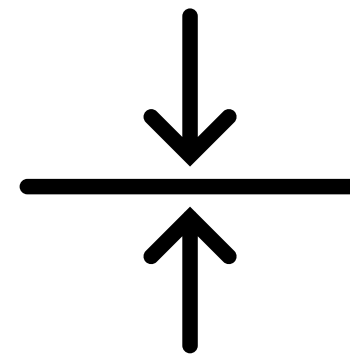
Promoting guideline implementation



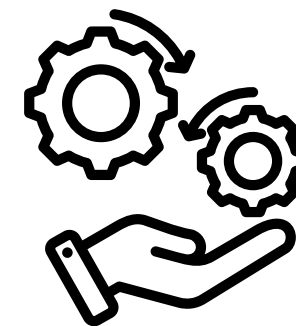
During the guideline development process: use of resources designed to increase implementability (e.g. AGREE-REX)



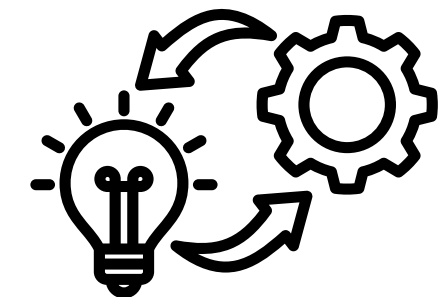
Establishment of the ERNICA central implementation support team (CIST) and identification of local implementation leads



Baseline overviews of current care practices



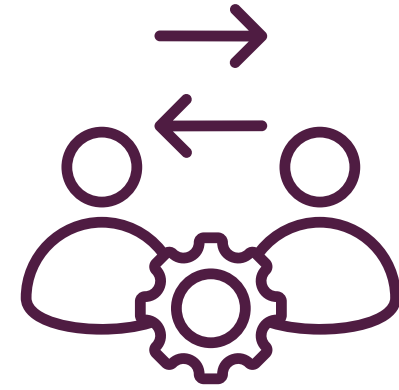
Identification of barriers and facilitators



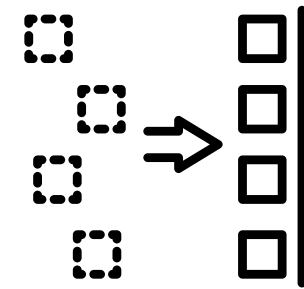
Collaborative development/selection of implementation strategies

(3)

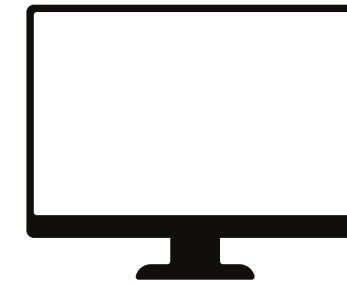
Measuring quality of care



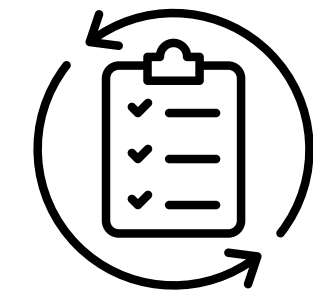
Use of a clinical audit (the EPSA) as a feedback mechanism to monitor guideline implementation & its impact



Alignment of EPSA core indicator sets with guideline-specific variables & inclusion of relevant data points



Efforts to (1) encourage audit participation & coordinated patient registration, (2) increase data quality (3) ensure sustainability (4) provide centre's with legal/regulatory support (5) reduce administrative burden



Provision of performance feedback in a way that stimulates behaviour change towards desired practices & Provision of support to centres to 'close the clinical audit cycle' through action planning

(4)

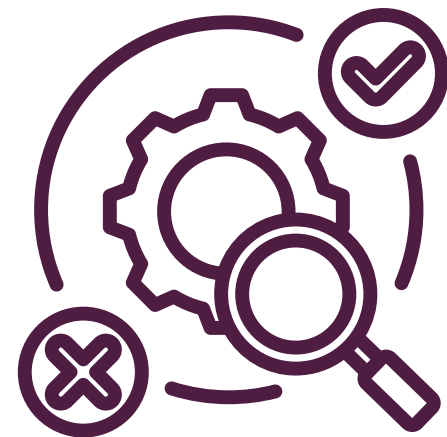
Evaluating clinical practice



Use of the EPSA as a way of re-auditing centre practices and associated outcomes



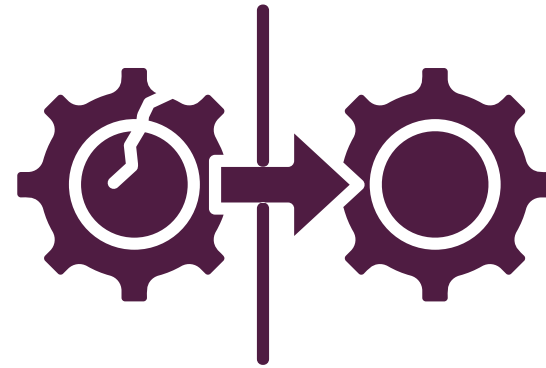
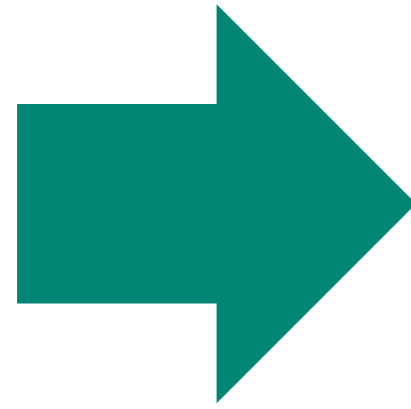
Aggregated EPSA data to provide insight into levels of practice, and outcome variation



Process evaluations with local teams (to explore the when, where, why and how behind successful or failed implementation)

(4)

Evaluating clinical practice



(Collaborative)
refinement of
implementation
strategies



Opportunities to capture
and build on
community learning
experiences



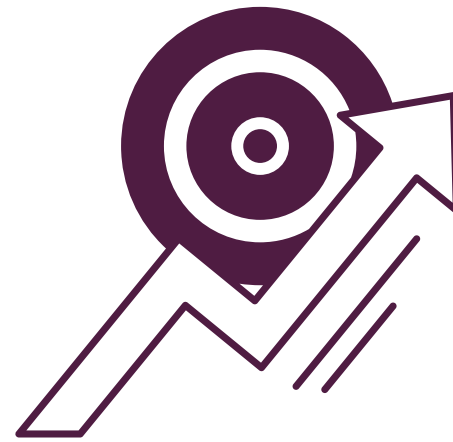
The need for new
guidelines/guideline
revisions?
& the identification of
'knowledge gaps' for
research prioritisation
(alongside patient
journeys)

(5)

Conducting research



Research focused on closing knowledge gaps

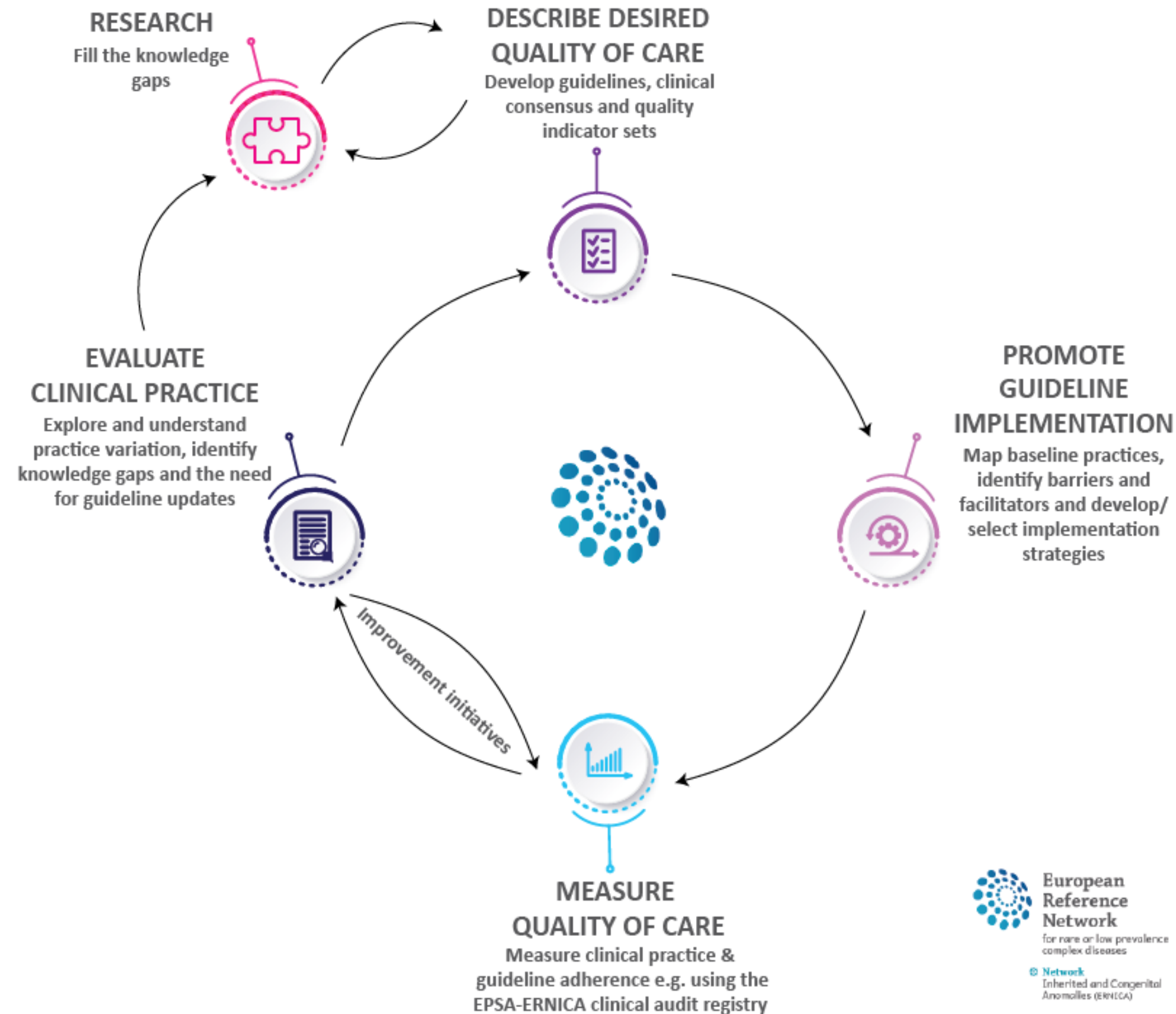


The development and/or appropriate use of core outcome sets (COS) and psychometrically robust PROMs

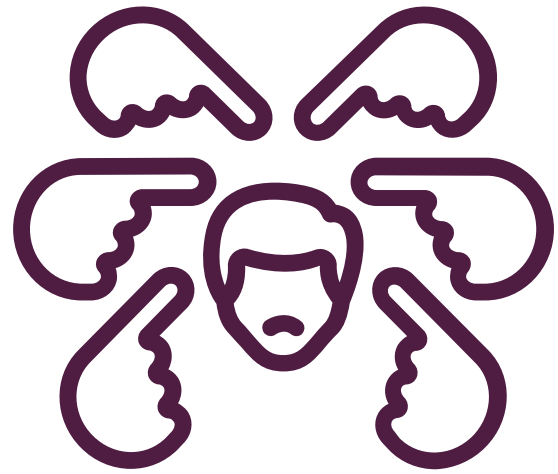


International collaboration

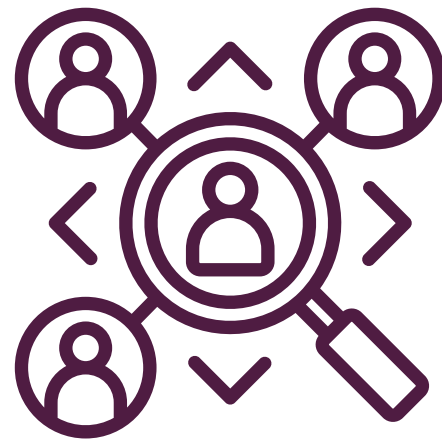
The ERNICA quality cycle



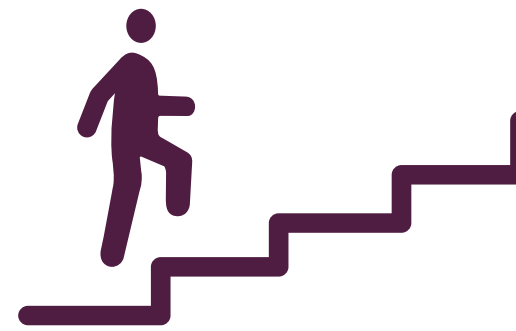
Applying & evaluating the approach



Non-judgemental
culture of improvement



Involvement of key
stakeholders



Start small.. focusing
on 3 diseases



Capture learning
points through
qualitative process
evaluation



Recognise limitations
and areas for ongoing
attention
(sustainability, legal
frameworks)



Healthcare systems
differ

Thank you for listening!

Any questions?

Email: o.spivack@erasmusmc.nl