

EURORDIS Open Academy Training

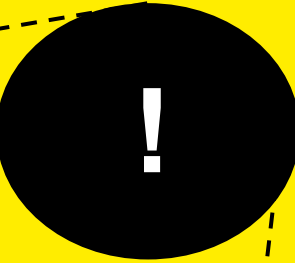


**From
engagement
to
shared
leadership and
beyond**

Barcelona | 2 June 2025

Tomasz Grybek

Diagnosis



Borys Michał

16 y.o.

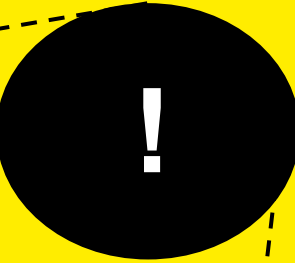
Metachromatic Leukodystrophy (MLD)

1-9/1 000 000 (Orphanet)

ORPHA: 512

D: 5,5

Odyssey



PITTSBURGH

PARIS

GDAŃSK

WROCŁAW

MILAN

From engagement to shared leadership and beyond



Numbers

1

2

3

4

22k

200m



Traveller's reflections

Lived experience is a **rare asset**

Partnership first of all is **an obligation** and then becomes cooperation

The less knowledge the **bigger risk transfer**

Economy

Unlimited needs

with

Limited resources

Attention

In an information-rich world, the wealth of information means a dearth of something else: a scarcity of whatever it is that information consumes (...) **the attention of its recipients.**

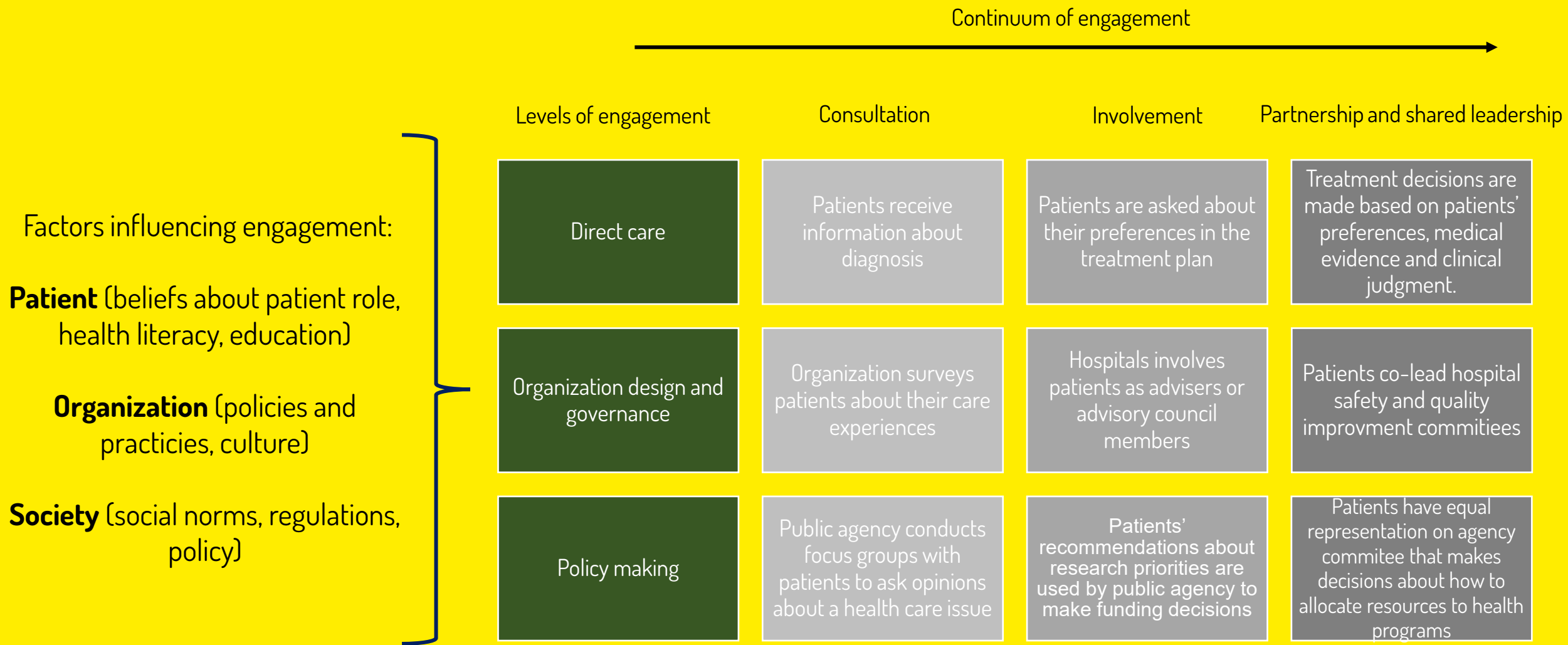
Herbert A. Simon

Economist's reflections

Find **your niche** – cooperation not competition

Have fun, let it drives you to action

Build culture of engagement 2.0, but... it takes two to tango



3Rs of PE

Responsibility

Reliability

Resources

A close-up, slightly blurred photograph of a person sitting on a motorcycle. A child is sitting on the person's lap, and the person's hands are resting on the child's arms. The person has a tattoo on their left forearm. The background is a soft-focus green field. The text "A goal without a plan is just a wish" is overlaid in white at the top right.

A goal without a plan is just a wish

Antoine de Saint-Exupéry

A close-up photograph of a person's hands holding a baby in a stroller. The person has a tattoo on their left forearm and is wearing a dark jacket. The baby is wearing a white shirt with a black floral pattern and a tan blanket. The stroller is dark blue with gold-colored buttons. The background is a blurred green field.

Plans are nothing; planning is everything

Dwight D. Eisenhower

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THANK YOU



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