

How do patient groups create
added value & impact: regional & national

Marek Lichota – Association „Appetite for Life”



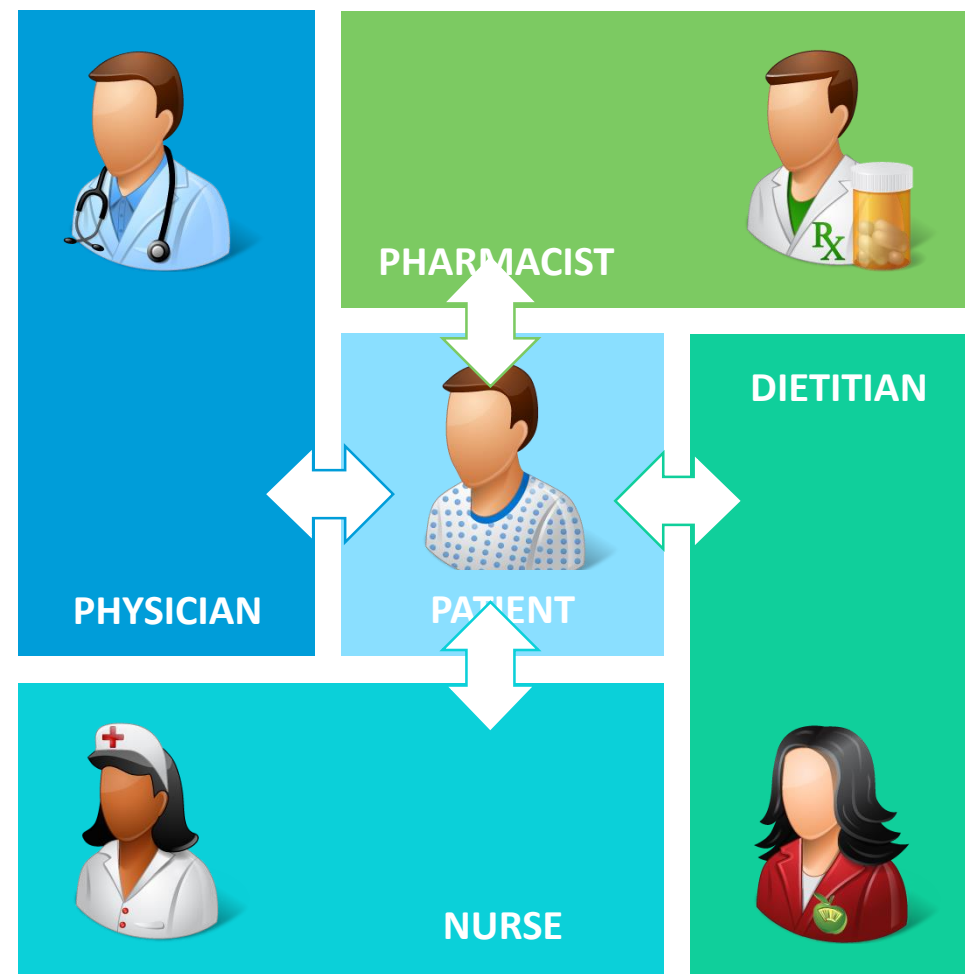
Nutrition TEAM

is a multidisciplinary team consulted to manage **PATIENTS** with complex nutritional needs (enteral and parenteral), which serves the primary responsibility of assuring that the patients receive **optimal nutritional care**.

The core members of the nutrition support team are

- **PHYSICIAN**,
- **NURSE**
- **DIETITIAN**,
- **PHARMACIST**.

AND **EMPOWERED PATIENT!**



“An empowered patient **has control over** the **management** of their condition in daily life. They **take action** to improve the quality of their life and **have the necessary knowledge, skills, attitudes and self-awareness** to **adjust their behaviour** and to **work in partnership** with others where necessary, to achieve optimal well-being.

Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the **capacity** to **participate in decisions** related to their condition **to the extent that they wish to do so**; to **become “co-managers”** of their condition in partnership with health professionals; and to develop **self-confidence, self-esteem** and **coping skills** to **manage** the physical, emotional and social impacts of illness in everyday life.”⁶

*EMPATHIE (Empowering Patients in the Management of Chronic Diseases) Summary Report 2014,
http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf
European Patients’ Forum - Background Brief: Patient Empowerment, 2015

INFORMATION

access to the right information, at the right time and way, leads patient's to take a more active role in decision-making.

A FACILITATING ENVIRONMENT

Being supported is a key component of patient empowerment.

SHARED DECISION MAKING

research which suggests that health outcomes are better in patients who are more involved in decisions about their treatment.

MUTUAL RESPECT

Partnership in which healthcare professionals are the experts in their knowledge of a disease, patients are the experts by experience.

HEALTH LITERACY

capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

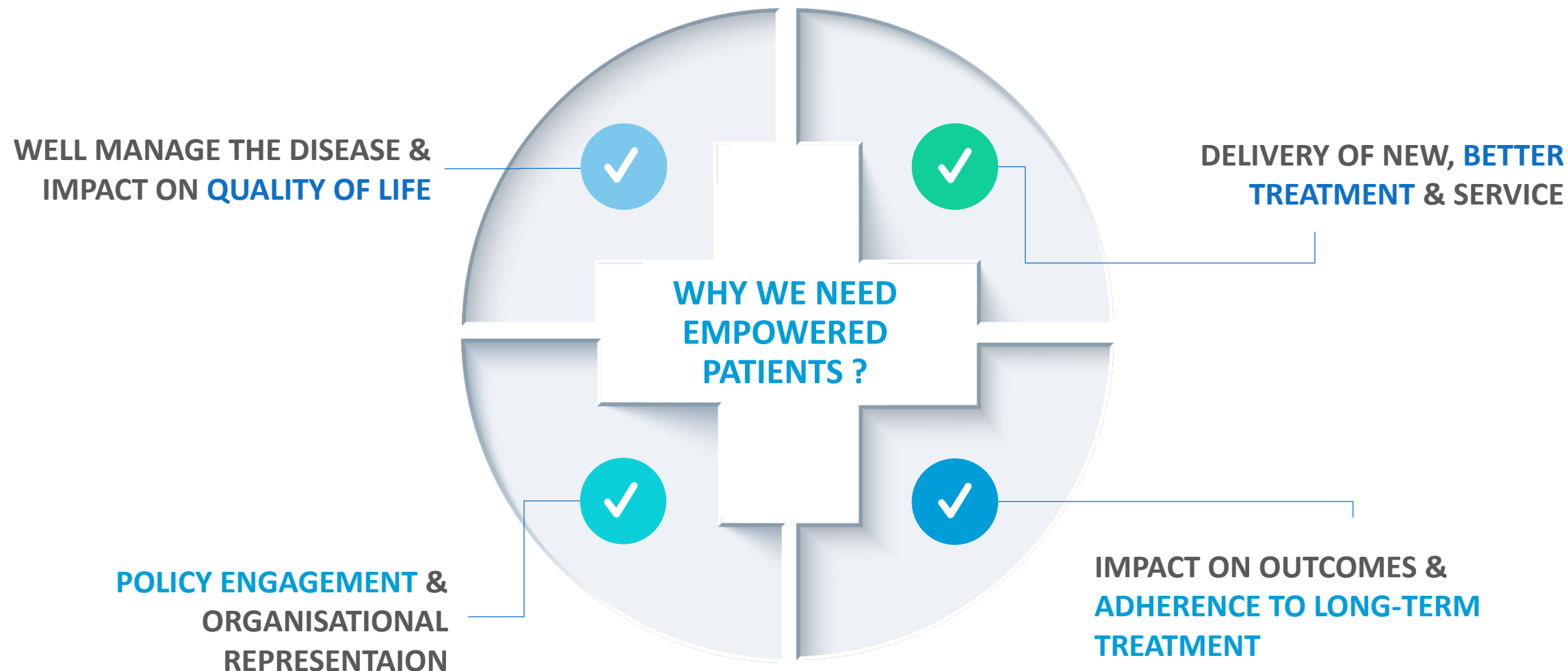
DIGITAL LITERACY

ability to find, evaluate, utilize, share, and create content using information technologies and the Internet.”.

SELF-EFFICACY

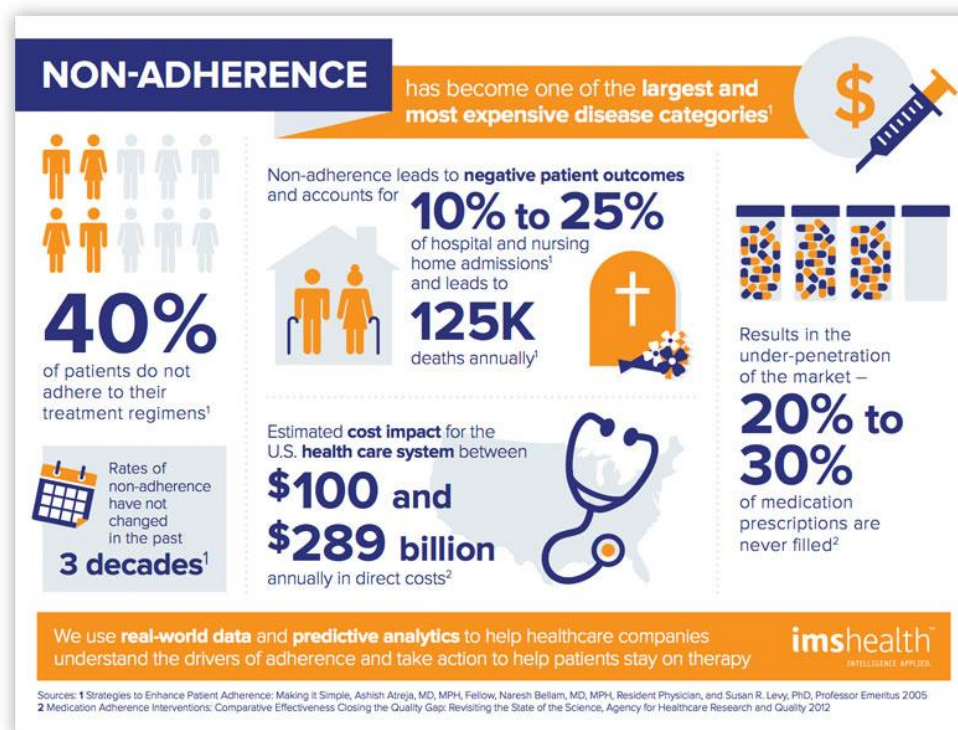
is belief in your ability to effect change in outcome, so that you can achieve your personal health goals..





MEDICATION ADHERENCE

is defined as ‘the extent to which the patients’ behaviour matches agreed recommendations from the prescriber’, emphasising the importance on the patients’ decisions.



194,500 deaths a year
in the EU
due to miss-dose and
non-adherence of
prescribed medication.

€ 125 billion annually
is estimated cost of non-
adherence in the EU

CAUSES OF POOR MEDICATION ADHERENCE

PATIENT-RELATED FACTORS

- lack of disease understanding
- lack of involvement in the treatment decision-making
- inadequate health literacy
- patient's health beliefs

PHYSICIAN-RELATED FACTORS

- prescribing complex drug regimens,
- failing to explain the benefits and adverse effects of a medication
- ineffective communication,

HEALTH SYSTEM/TEAM BUILDING-RELATED FACTORS

- limiting the health care coordination and the access to care.
- prohibitive drug costs or copayments also contribute to poor medication adherence.
- health information technology is not widely available



**WE MAY NOT BE ABLE TO
SOLVE ALL OF YOUR
PROBLEMS, BUT WE CAN
PROMISE YOU WON'T HAVE
TO FACE THEM ALONE.**



IMPROVE QUALITY OF LIFE

WE PROVIDED MORE THAN
60 AMBULATORY PUMPS
AND **4 000** OF LIFELINE SETS.





DELIVER BETTER SERVICE AND CARE




OVER PAST 6 YEARS WE GAINED
MORE THAN **250 000 EURO**
FOR **SUPPLEMENTARY MEDICAL**
COSTS AND **PROJECTS** RELATED TO
QoL OF HAN AND IBD PATIENTS.



optimal
nutritional care
for all



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@ONCAcampaign

#nutritionalcare



POLICY ENGAGEMENT

WE APPROACHED **NATIONAL & EU PARLIAMENT** AND OTHER **GOVERNMENT BODIES** RESPONSIBLE FOR **HEALTH POLICY**.





RAISING AWARENESS

WE SHARED **PATIENT PERSPECTIVE**
AND RAISED IMPORTANCE OF **NUTRITION**
IN ANY TREATMENT PLAN ON MORE THAN
60 DIFFERENT **MEDICAL CONFERENCES**
AND CONGRESSES, WHICH REACHED
AROUND **6 000** MEDICAL PROFESSIONALS.





SHARING INFORMATION



WE ORGANIZED 5 CONFERENCES
AND MULTIPLE WORKSHOPS FOR
NEARLY 2 000 PATIENTS AND
STUDENTS OF MEDICAL
UNIVERSITIES.





SHARING EXPERIENCE



WE IMPROVE **SKILLS AND KNOWLEDGE**,
OF AROUND **300** PATIENTS, WHO JOINED
OUR PATIENTS SUPPORT GROUP MEETINGS TO
OVERCOME DAILY PROBLEMS & ROUTINE.

WE WERE ALSO INVOLVED IN THE PROCESS OF
CREATION OF **NUTRITION FOCUSED** PATIENTS
GROUPS AT THE INTERNATIONAL LEVEL.





INFLUENCE

Dear Marek! Finally Estonian Clinical Nutrition Patient Organisation established! You had your share in it! Thank you! And for hosting my dear patients! Regards from Estonia! Liis



Obrigado 😊