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Redefining empowerment from a patient perspective

Walter Atzori, European Patients' Forum
Riga, 12 May 2015

“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”



EPF Mission and vision

European Patients' Forum:

- Umbrella organisation
- Active since 2003
- 64 members



Our Mission!

To ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU

Levels of Patient Empowerment

individual

Micro level

Individual patient, relationship with health professional, family context (e.g. self-management skills, shared decision-making process)



Meso level

Health care organisations / environments, care delivery processes (e.g. design of the environment, how quality is assessed, patient feedback systems)



Macro level

Policies, programmes at national (regional) and EU level (e.g. information to patients, patients' rights laws, EU legislation, health professionals' training curricula..)



collective

Defining Patient Empowerment

“ Patient empowerment is a process whereby the patient gains **control over the management** of their condition in daily life, **take action to improve their quality of life** and has the necessary **knowledge, skills, and attitudes** to adjust their behaviours and to **work in partnership with healthcare professionals** to achieve optimal wellbeing”

- **Empowerment vs involvement/participation**

- Empowerment is a process that manifests itself in concrete actions (involvement/participation)



Defining Patient Empowerment

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GREEN= empowerment

PURPLE= involvement participation

- **Empowerment vs involvement/participation**
 - Empowerment is a process that manifests itself in concrete actions (involvement/participation)

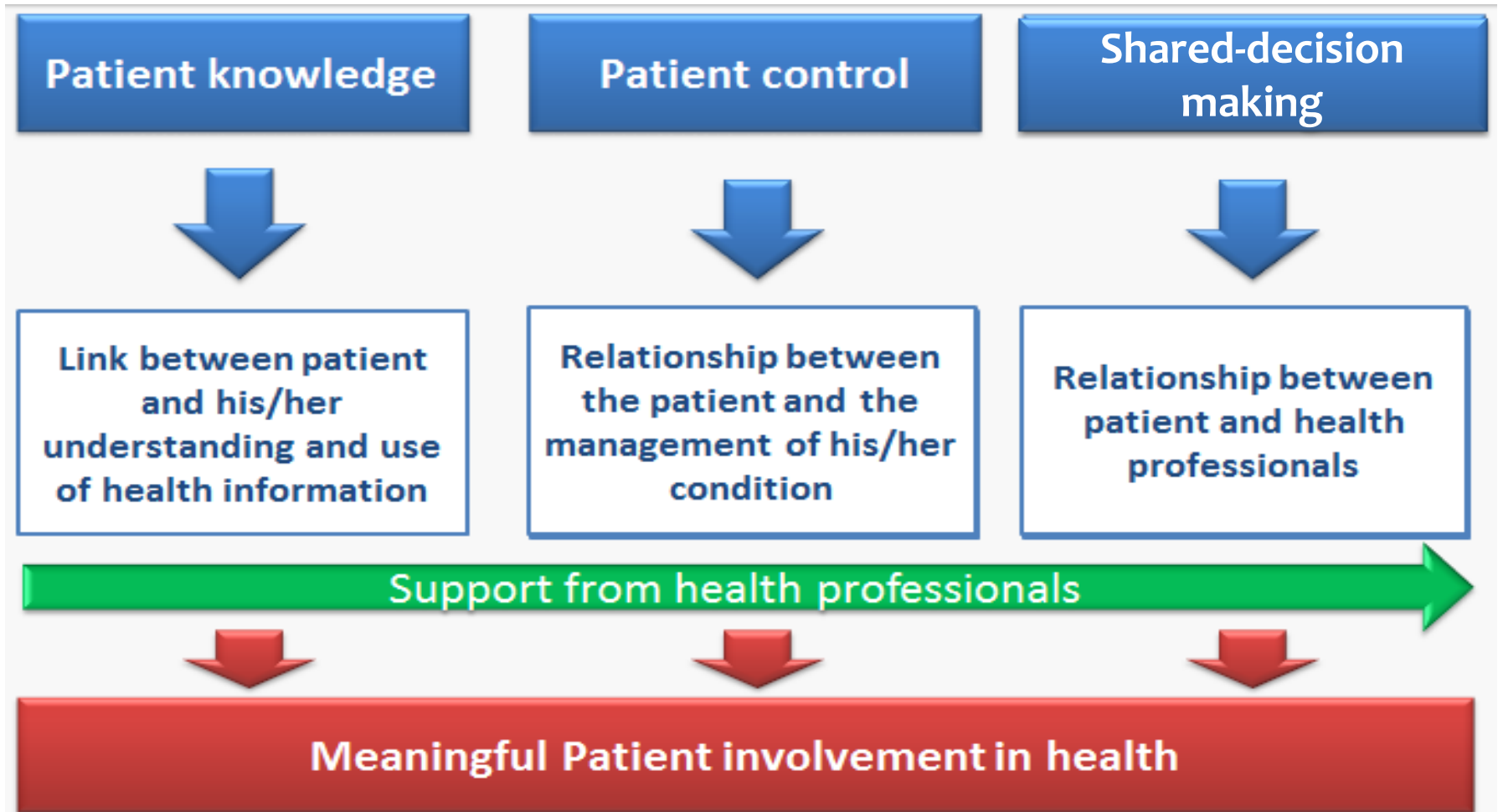
Defining Patient Empowerment

- **Empowerment vs empowerment interventions**
 - Empowerment interventions aims at equipping patients with the capacity to participate in decisions relating to their condition to the extent they wish to do so
 - Empowerment interventions require actions at meso and macro level



'I've got a patient who needs to chat to someone...Have you got anyone who's completed the 'verbal communication with patients in a personal, supportive but not disempowering' course?'

SUSTAINS Patient Empowerment model



eHealth and patient empowerment



High expectations among non-users of eHealth



Impact of telemedicine on the control dimension



Impact of patient accessible EHR on the participation dimension



Key importance of health literacy and availability of high quality patient friendly information

Chain of TRUST project



Patients: eHealth and empowerment

- ❖ **92%** of **patients** are willing to play a more active role in managing their own condition
- ❖ **60%** of patients would be **willing to use eHealth** in the short-medium future
- ❖ ... but only **48%** thinks they are ready to handle the additional responsibilities presented by eHealth



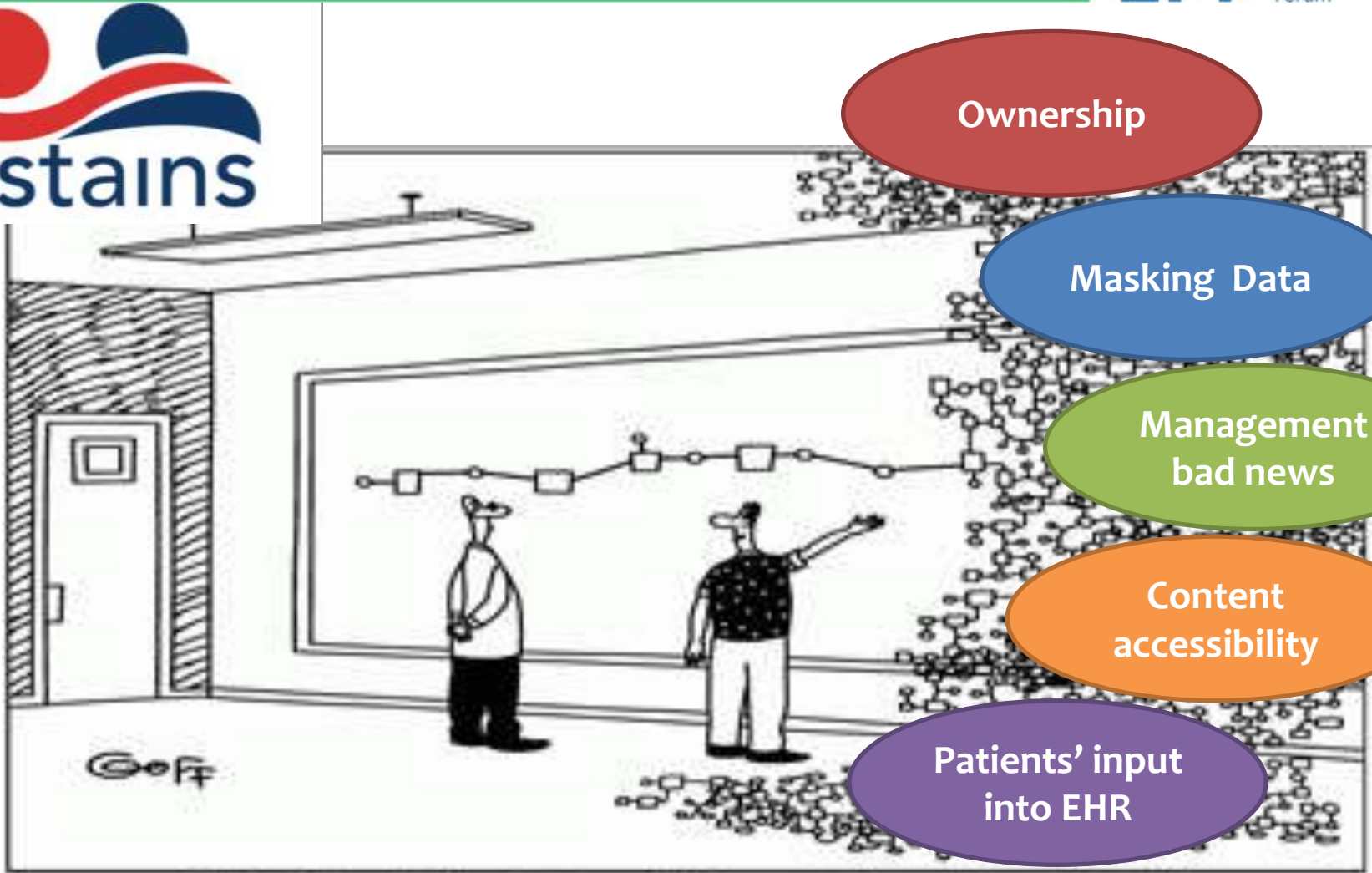
How about health professionals?

- ❖ **70%** health professionals would be **willing to use e-health** in the short-medium future
- ❖ ...and only **29%** believe that their patients will be in the position to use e-health service safely

Chain of **TRUST**

Understanding patients' and health professionals' perspective on **Telehealth** and building confidence and acceptance

SUSTAINS project on patient access to EHR



Ownership

Masking Data

Management bad news

Content accessibility

Patients' input into EHR

"This is where the idea for the new EHR starts getting a little complicated."

Evidence on Empowerment process

- **Increased patient control** over his/her health status and management of chronic conditions
- **Patients are more prepared** for face to face visits
- Quality of consultations/interaction is higher as patients are more **knowledgeable** about their health (**concordance**)
- Patients prepare questions in advance
- Patients are able to draw HCPs attention to issues important to them
- **Adherence** is improved as a result of **ownership**

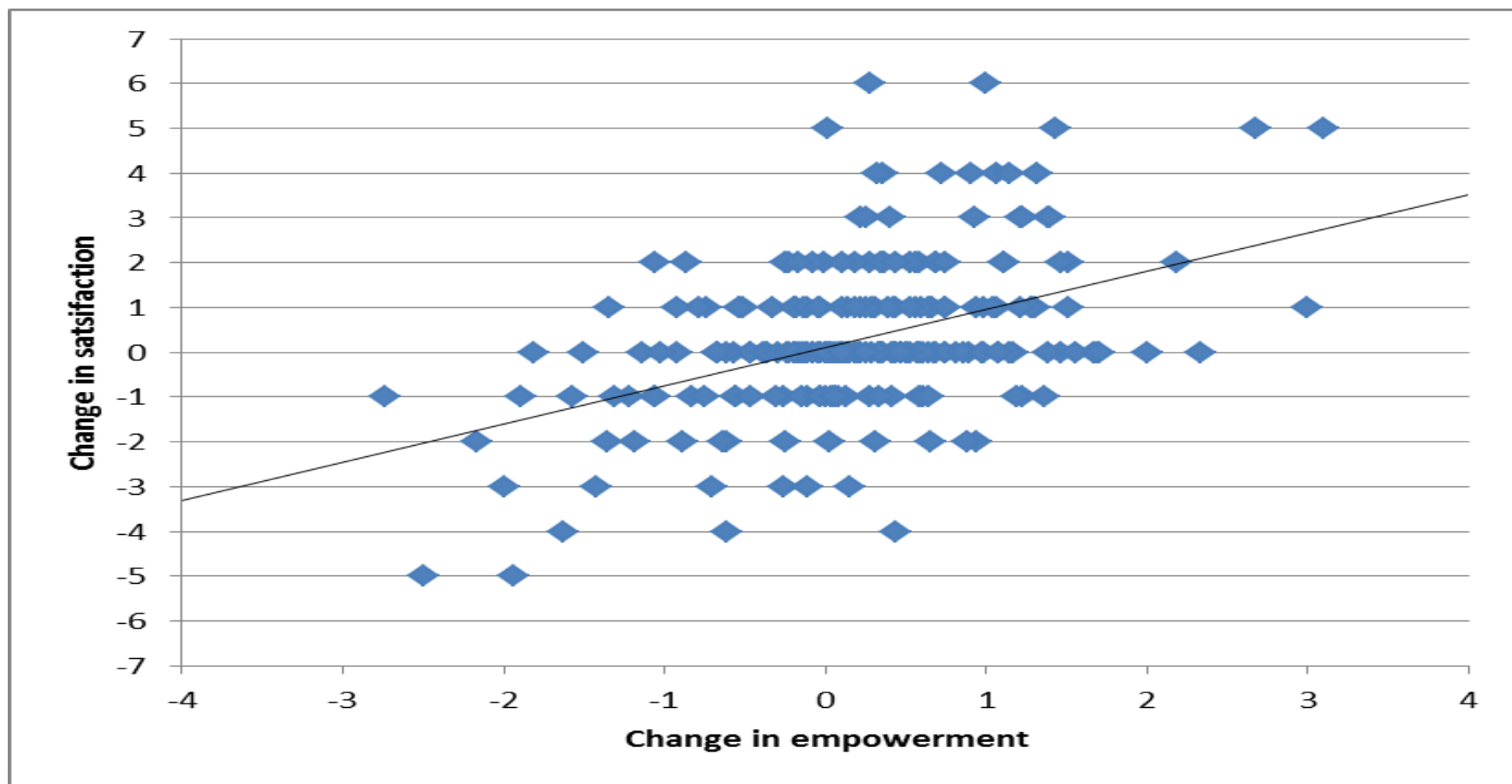
Empowerment and satisfaction

More empowered patients are in general more satisfied with the relationship with health professionals



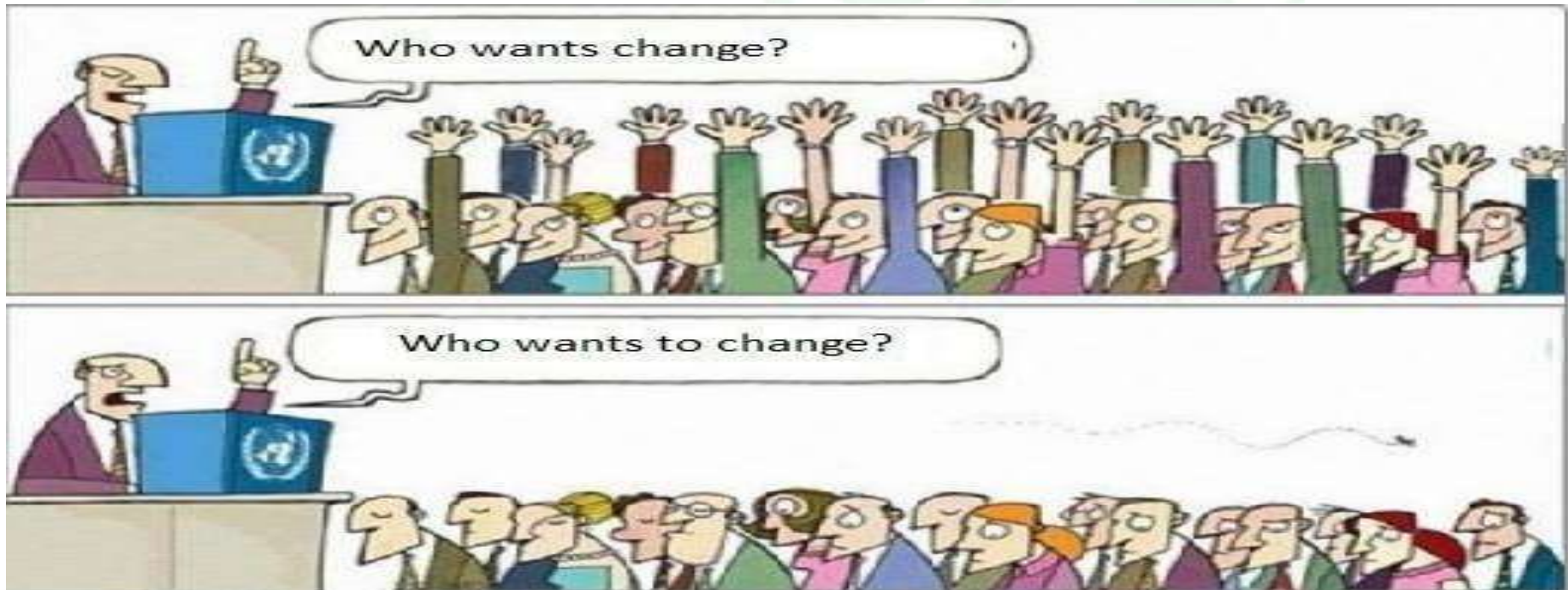
Empowerment and satisfaction

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SUSTAINS project on EHR

- Resolving the question of **patient access to their EHR** is an important prerequisite to enable patient empowerment
- Cultural dimension of eHealth
- **If there is no resistance there is no real change!**



Things to remember about empowerment

- A process (not static)
- Non-binary (there are degrees of empowerment)
- Non-linear (going ‘back’ as well as ‘forward’)
- Context-dependent
- Something that cannot be imposed by others, but can be facilitated
- Both individual (patient) and collective (the patient community).

EMPOWERED PATIENTS ARE AN ASSET TO SOCIETY

We want to be **full partners** in the management of our conditions according to our individual capacities and situation. We need to be empowered to do so. Empowerment starts with **tailored high-quality information** and **health literacy**, to enable us to make **informed choices** about our treatment and care. Empowered patients are good for health systems. We take responsibility for our care in **equal partnership** with health professionals. We also take preventive measures, seek earlier diagnosis and adhere to treatment, which can **reduce healthcare costs** in the long run.

➔ **ADOPT AN EU STRATEGY ON PATIENT EMPOWERMENT, INCLUDING AN ACTION PLAN ON HEALTH LITERACY AND HIGH-QUALITY INFORMATION FOR PATIENTS ON ALL ASPECTS OF OUR CARE.**

THANK YOU FOR YOUR ATTENTION!

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