

Standards of Excellence for Patient Organisations...

10th SPAEN Annual Conference

Sunday, February 2nd, 2020 – Early Breakfast Session

Markus Wartenberg

The Next 50 Minutes...

- **Setting The Scene:**
“Standards of Excellence for Patient Organizations”...
- **Practical experience / example** from South Africa
Lauren Pretorius (ZA)
- **Auditorium:**
What are **your experiences with / examples of** “Standards of Excellence”?
What activities / processes / documents are you using in your organizations?

Why – When – What? (1)

- Most patient organizations are “non-profits” (charities)

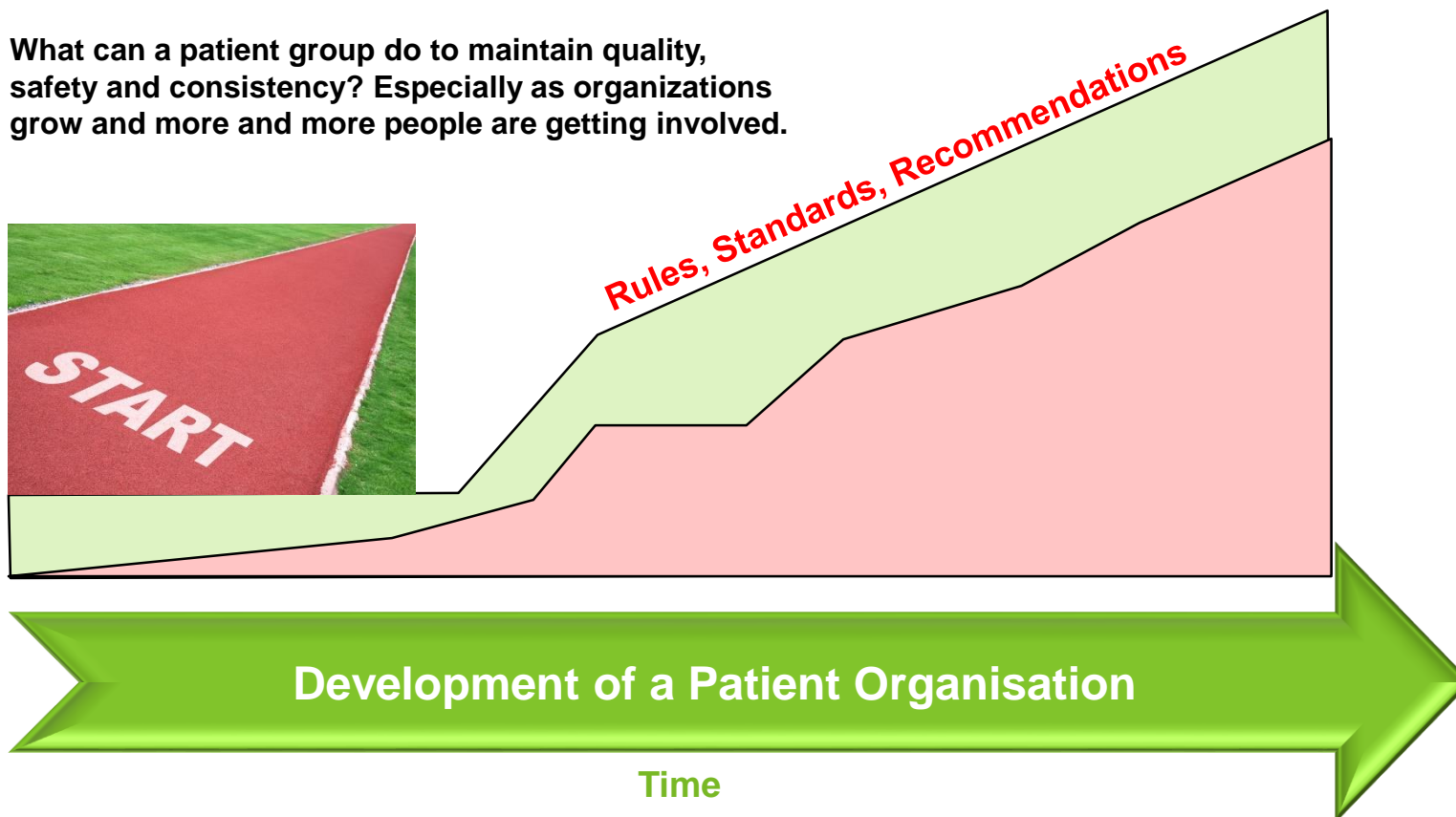
They are working hard and engaged for patients/carers – for the public - but often they also need trust and support from the public / from different stakeholders...

- “Standards for Excellence” are rules, regulations, recommendations, directions for nonprofits = organizational governance, management, policies, procedures and legal compliance at any stage of a nonprofit’s lifecycle.



Patient Organization “Lifecycle”

What can a patient group do to maintain quality, safety and consistency? Especially as organizations grow and more and more people are getting involved.

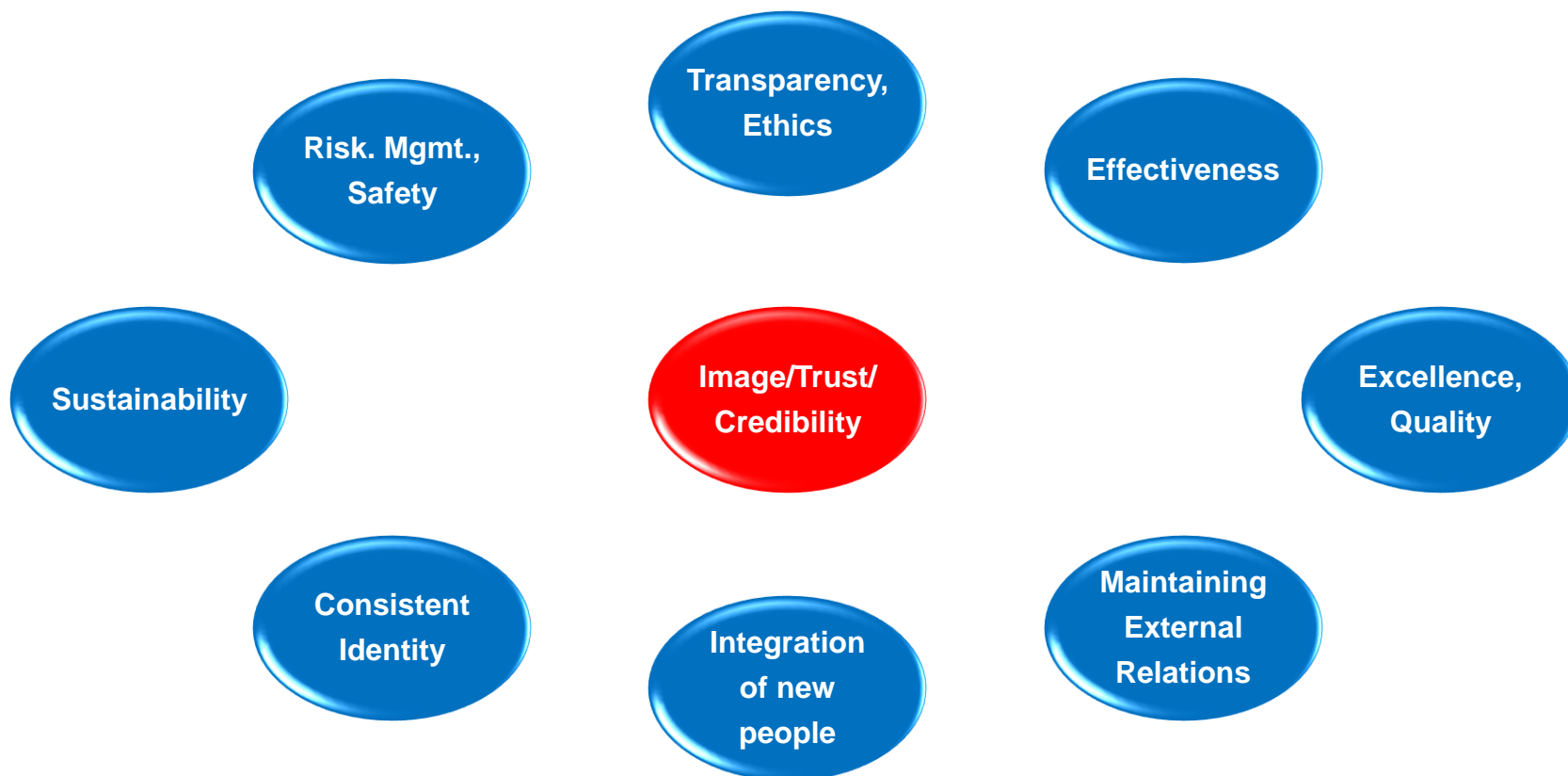


Why – When – What? (2)

- “Standards of Excellence” aim to raise the level of accountability, transparency, quality and effectiveness to foster excellence and inspire credibility / trust... (Also to avoid mistakes and misconducts!)
- The nature and scope of the standards are related to –
 - the stages within the lifecycle
 - type and size of the organization
 - the number and type of people that are involved
 - the stakeholders with whom the organization collaborates.
- It is important to think about with whom the organization
 - is dealing internally
 - is maintaining external relationship.



Why – When – What? (3)



Six Main Sections

Section 1:
**Mission, Strategy
and Evaluation**

- MISSION, VISION, VALUES, IMPACT
- PLANNING STRATEGICALLY
- ORGANIZATIONAL EVALUATION
- EVALUATION OF PROJECTS,
SERVICES, ACTIVITIES
- STRATEGIC PARTNERSHIPS

Six Main Sections

Section 2:
**Leadership, Board,
Staff and Volunteers**

- LEADERSHIP AND GOVERNANCE
(Mainly the Board)
- LEADERSHIP AND OPERATIONAL
MANAGEMENT, EMPLOYEES,
FREELANCERS, VOLUNTEERS
- EDUCATIONAL STRATEGY
- DIVERSITY, EQUITY AND
INCLUSION

Six Main Sections

Section 3:
**Legal Compliance
and Ethics**

- MAINTAINING LEGAL COMPLIANCE
- REQUIRED PUBLIC DISCLOSURES
- REPORTING MISCONDUCT AND WHISTLEBLOWER PROTECTION
- CONFLICTS OF INTEREST
- ETHICS

Six Main Sections

Section 4: Finance and Operations

- FINANCIAL BUDGETING,
REPORTING AND MONITORING
- INTERNAL CONTROLS AND
FINANCIAL POLICIES
- PERSONNEL POLICIES
- ADMINISTRATIVE POLICIES
- RISK MANAGEMENT AND
INSURANCE

Six Main Sections

Section 5:
**Resource
Development**

- RESOURCE PLAN
- SOURCES OF INCOME
- FUNDRAISING ACTIVITIES
- DONOR RELATIONSHIPS
AND PRIVACY
- ACCEPTANCE OF GIFTS

Six Main Sections

Section 6:
**Services, Engagement,
Communications and Advocacy**

- SERVICES TO PATIENTS/CARERS SUCH AS INFORMATION, EDUCATION AND SUPPORT
- SERVICES TO THE MEDICAL COMMUNITY AND OTHER STAKEHOLDERS
- COMMUNICATION STANDARDS TO DIFFERENT STAKEHOLDERS
- ENGAGING IN LOBBYING AND POLITICAL ACTIVITY

Some Selected (Practical) Activities/Documents...

Strategic Planning:
Vision, Mission,
Values

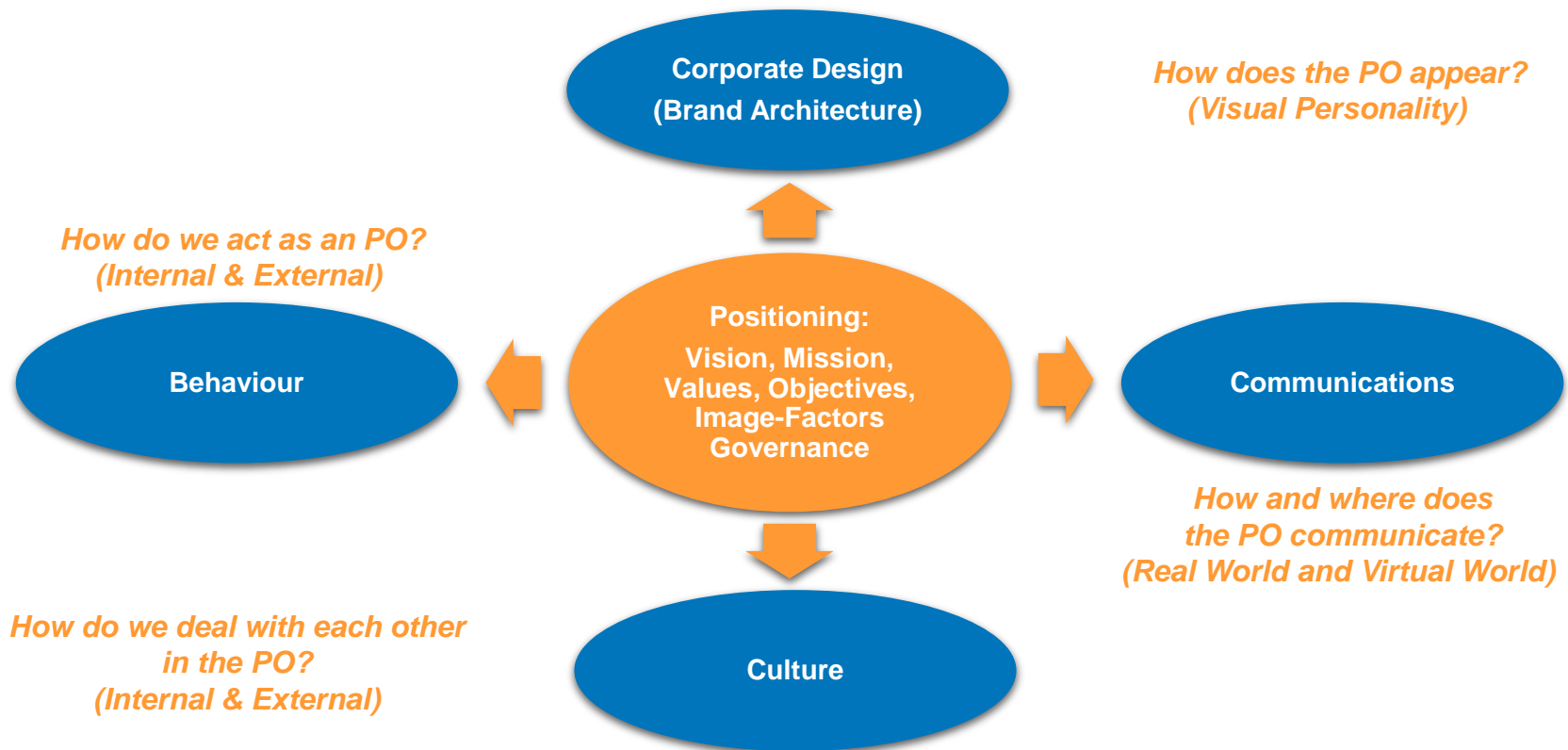
Corporate Identity

Strategic Planning: Vision, Mission, Values <hr/> Corporate Identity			

Mission & Vision: Part Of The “Strategy Process”...



Core Part Of A PO's Identity...



Some Selected (Practical) Activities/Documents...

**Strategic Planning:
Vision, Mission,
Values**

Corporate Identity

**Association:
Statutes and
Bylaws**

**Data Protection:
Consent, Storage,
Access, Handling,
etc.**

**Insurance for the
Association, Board,
Employees**

**Contracts for
Employees &
Freelancers**

**Financial &
Reimbursement
Workflow**

**Educational
Strategy**

**Boards, Committees,
Working Groups:
Objectives, Tasks,
Rules & Regulations**

**Working with
Industry: Code of
Conduct / Practice**

**Generating and
Providing Patient
Information**

**Finding, Selecting
and Managing
Volunteers**

**Support-Hotlines
and
Regional Support
Groups**

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