B1: Co-designing in partnership with patients

International Forum on
QUALITY & SAFETY
in HEALTHCARE
COPENHAGEN

Adapting to a changing world: equity, sustainability and wellbeing for all

@QualityForum #Quality2023

Institute for Healthcare Improvement

BMJ

Involving and Working in Partnership with Patients in Patient Safety

Joan Russell, Head of Patient Safety, Policy and Partnerships, NHS England

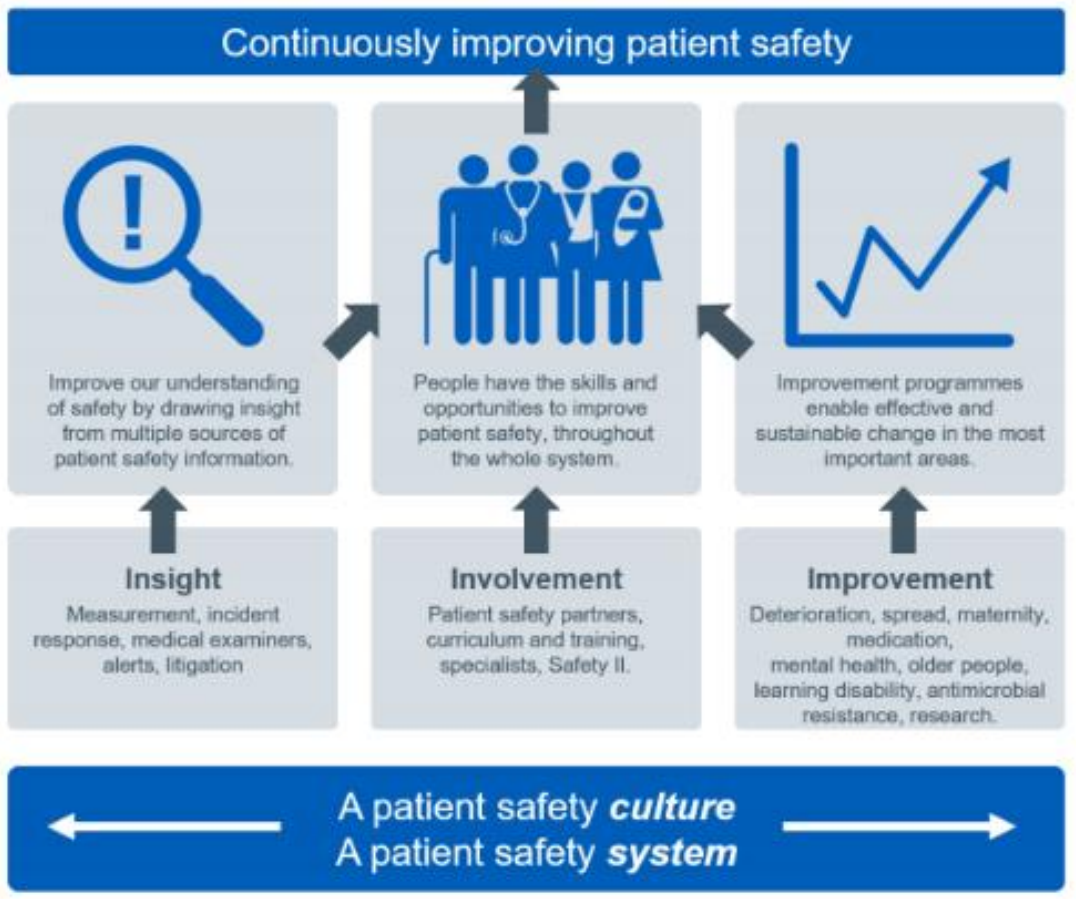
Douglas Findlay, Patient Safety Partner, NHS England

May 2023

NHS Patient Safety Strategy

The NHS Patient Safety Strategy provides a structure for all our patient safety work, including within primary care

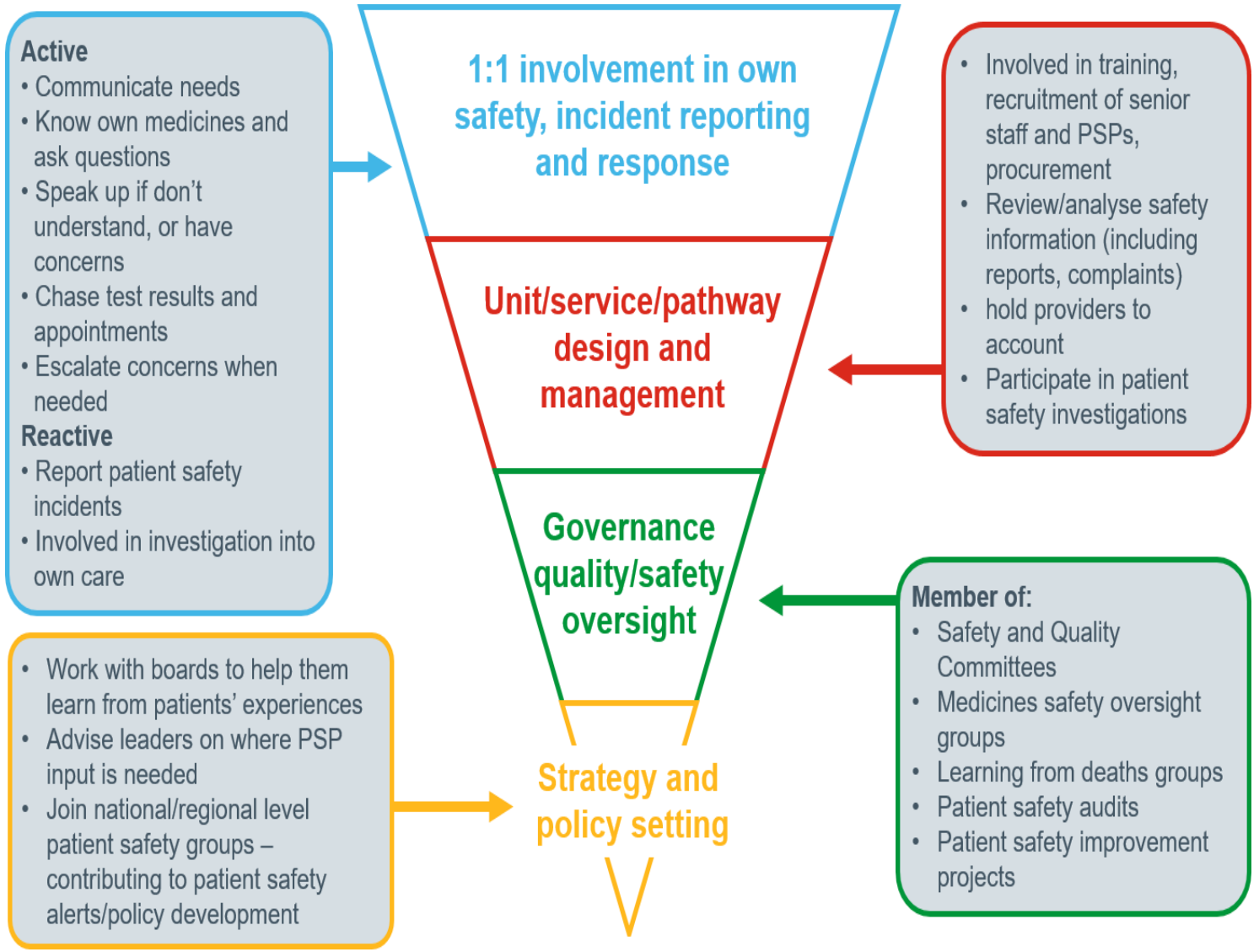
- **Patient safety culture** –visible leadership promoting openness, just culture and continuous improvement, valuing diversity and equality.
- **Patient safety systems** – governance, accountability, supporting whole systems (ICS) and systematic improvement, primary care, intelligent use of digital, inequalities reduction.
- **Insight** – a whole organisation commitment to identifying risks, recording and responding to incidents, understanding what contributes to safety, identifying how we normally keep our patients safe
- **Involvement** – a focus on people, giving them the skills and support they need, fundamentally involving patients and the public, recognising the need for specific expertise
- **Improvement** – identification and implementation of improvement priorities using quality improvement science to continuously reduce risks to patients.



Involving patients

"Patients and their carers should be present, powerful and involved at all levels of healthcare organisations from wards to the boards of trusts..."

Don Berwick A promise to learn - a commitment to act (2013)



Our vision

“For patient safety to be at its most effective it is vital to partner with those that receive care. The perspective, knowledge, and experience of patients, carers and families, as well as their ability to challenge, must become a key part of patient safety governance and improvement work across the NHS.”

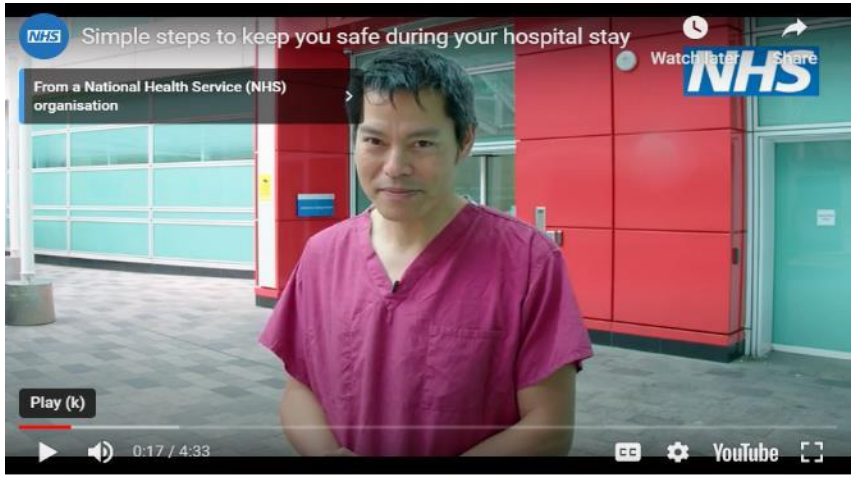
Aidan Fowler

National Director of Patient Safety

Involving patients in patient safety (IPIPS)

The Framework for involving patients in patient safety is in two parts:

- **Part A -** Describes how organisations should support patients, their families and carers to be directly involved in their own or their loved one's safety eg video Simple steps to keep you safe during your hospital stay



- **Part B** – Describes how organisations should support patient safety partners (PSP) to be involved in wider governance and leadership of safety activities.

  PSPs are patients, carers, family members or other lay people recruited to work in partnership with staff to influence and improve the governance and leadership of safety within an NHS organisation.

Framework

Part A: Involving patients in their own safety

- Encouraging patients to ask questions
- Individual information sharing sessions
- Information campaigns
- Incident reporting systems
- Involvement in the response to a patient safety incident including any investigation

Patient Safety Partners (PSPs)

Introduction of PSPs will take time – organisations should first assess their readiness to engage

Benefits of PSP involvement include:

- promotes openness and transparency
- helps the organisation to know what is important to patients
- helps the organisation identify risk by hearing what feels unsafe to patients
- helps the organisation produce patient information that patients understand and can access
- supports the prioritisation of risks that need to be addressed and subsequent improvement programmes

Roles for PSPs

- Membership of safety and quality committees whose responsibilities include the review and analysis of safety data
- Involvement in patient safety improvement projects eg in defining, designing and delivering safety objectives and monitoring outcomes that are patient centred.
- Working with organisation boards to consider how to improve safety
- Involvement in staff patient safety training
- Participation in investigation oversight groups
- Staff recruitment eg by shortlisting candidates and designing interview questions and sitting on interview panels
- Encouragement of patients, families and carers to play an active role in their safety, to report incidents and participate in their investigation to promote learning, and to help design safer systems of care
- Assist with the development of role/task specifications/profiles for future PSPs

PSP implementation principles 1-4

1. **Commitment to involving PSPs in patient safety:** The organisation should express a commitment to the involvement of PSPs and promote their recognition throughout the organisation.
2. **Creating a framework to develop and support PSP involvement:** There is no contract of employment between PSPs and the organisation. Instead, the relationship is based on mutually agreed expectations about the role.
3. **Inclusive approaches to attracting PSPs:** The organisation works to involve PSPs who reflect the diversity of the local community.
4. **Developing PSP roles and task profiles:** The organisation develops appropriate roles for PSPs in line with its aims and objectives, which are consistent with this guidance and which are valued by the PSPs in those roles.

PSP implementation principles 5-9

5. Safeguarding PSPs, staff and patients: The organisation is committed to ensuring that, as far as possible, PSPs are protected from any emotional and financial harm arising from their role.

6. **Recruiting PSPs:** The organisation is committed to using fair, efficient and consistent recruitment procedures for all potential PSPs.

7. **Induction and training for PSPs:** Clear procedures are followed when inducting new PSPs to their role, the organisation and relevant policies.

8. **Supporting PSPs:** The organisation takes account of the varying support needs of PSPs and provides for them.

9. **Valuing and recognising PSP contributions:** The whole organisation is aware PSPs need to be given recognition.

Requirements in Patient Safety Strategy

The NHS Patient Safety Strategy includes the ambition for all safety-related clinical governance committees (or equivalents) in NHS organisations to include two PSPs by July 2022, and for them to have received required training by July 2023.

Next steps

A handful of ‘exemplar trusts’ are being engaged to work with directly, to learn about the challenges and support implementation.

Regular updates will be provided for the wider NHS.

Co-design group

- Eighteen organisations currently involved
- Providers and commissioners from across England
- Initial priority – recruitment
- Subsequent phases may address other elements of the Framework where the need for support with implementation is identified.
- Regularly update content on PSS Future Collaboration Platform

NHS Patient Safety Syllabus

- **Patient Safety Syllabus (version 2) published 2021**

- **Levels 1 and 2 launched October 2021 on the e-Learning for Healthcare platform**

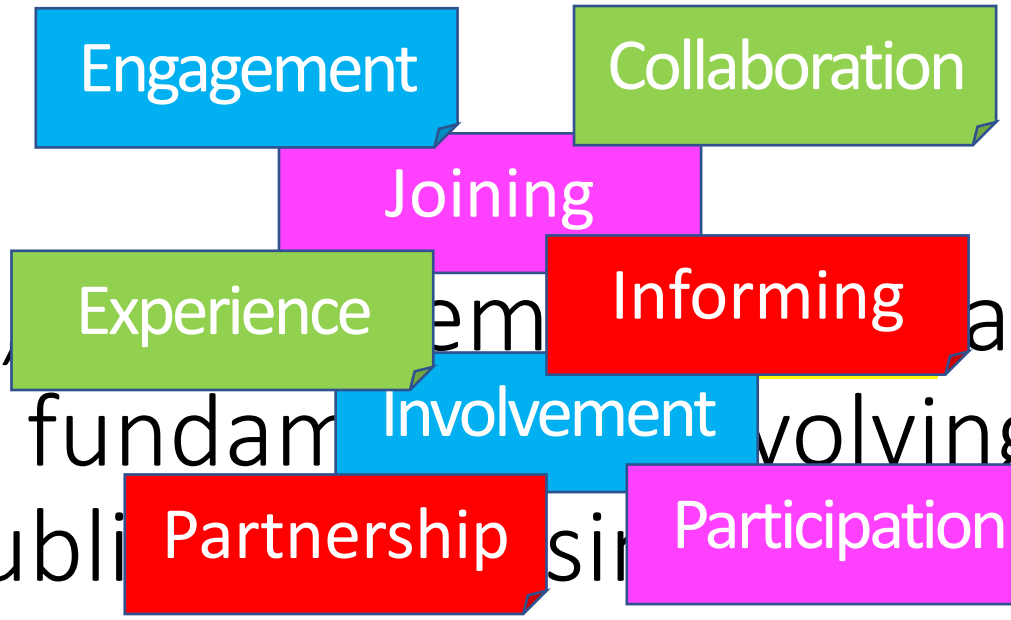
  https://www.e-lfh.org.uk/programmes/patient-safety-syllabus-training/

- **Levels 3-5**
  - Detailed curriculum guidance published for Levels 3 to 5
  - Content currently being developed. Training to commence Autumn 2023
  - Abridged version for Patient Safety Partners being scoped.

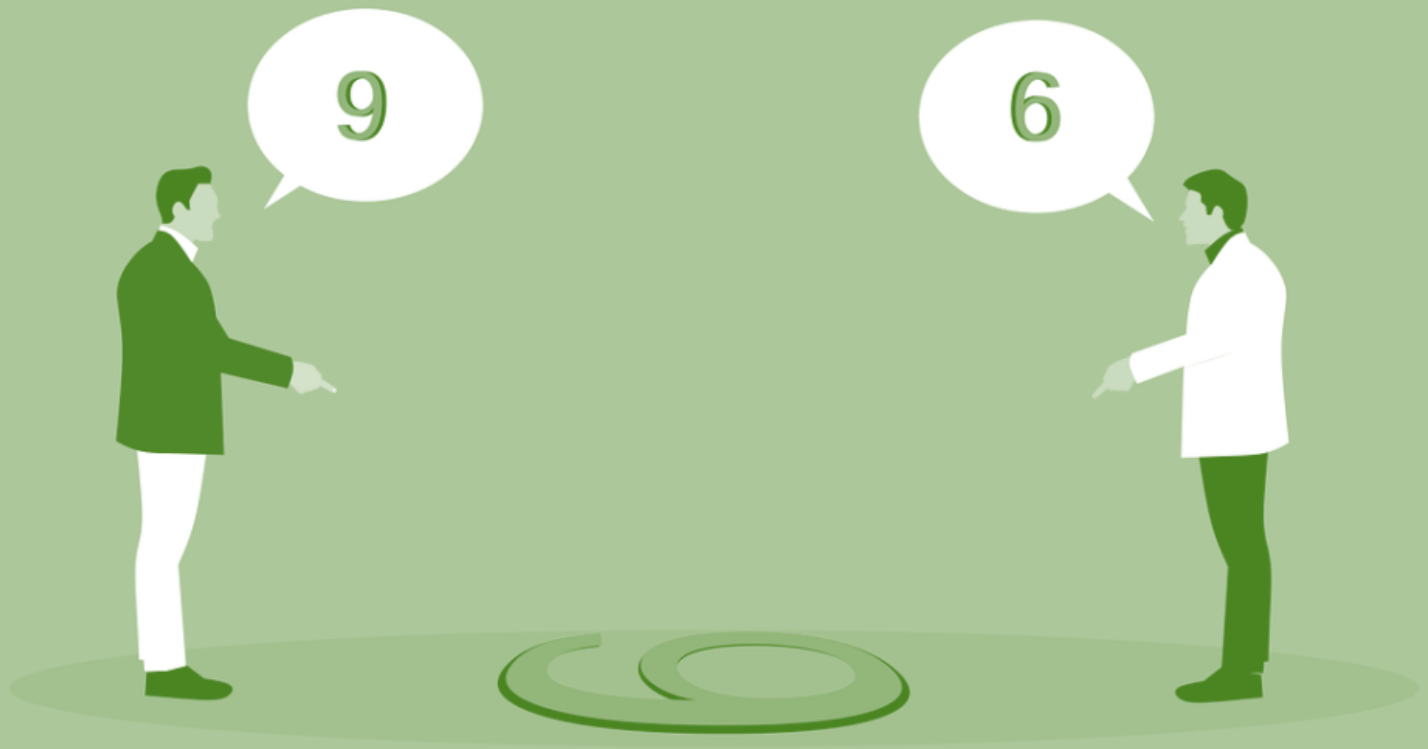
Curriculum structure

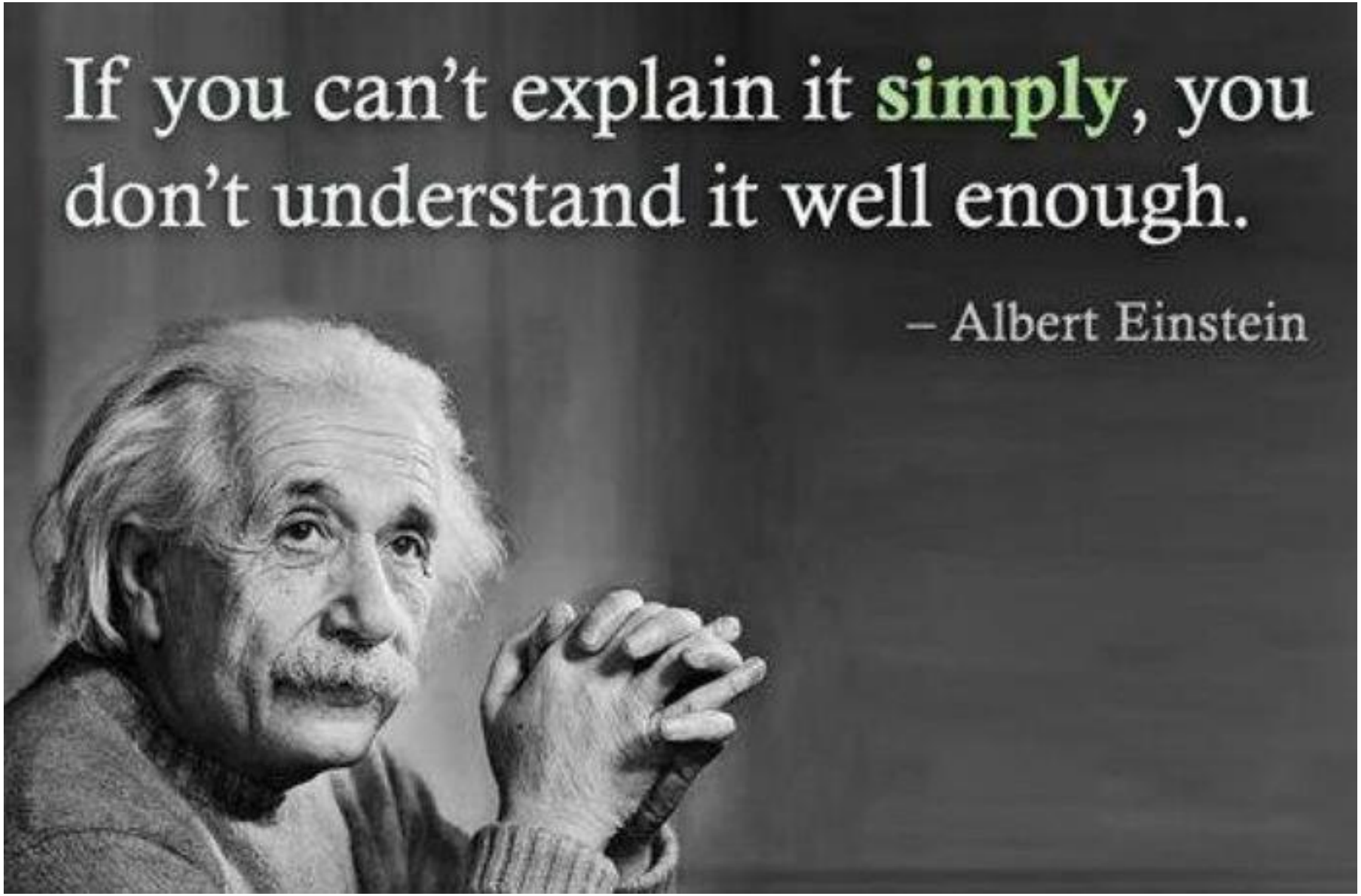
The words we use …

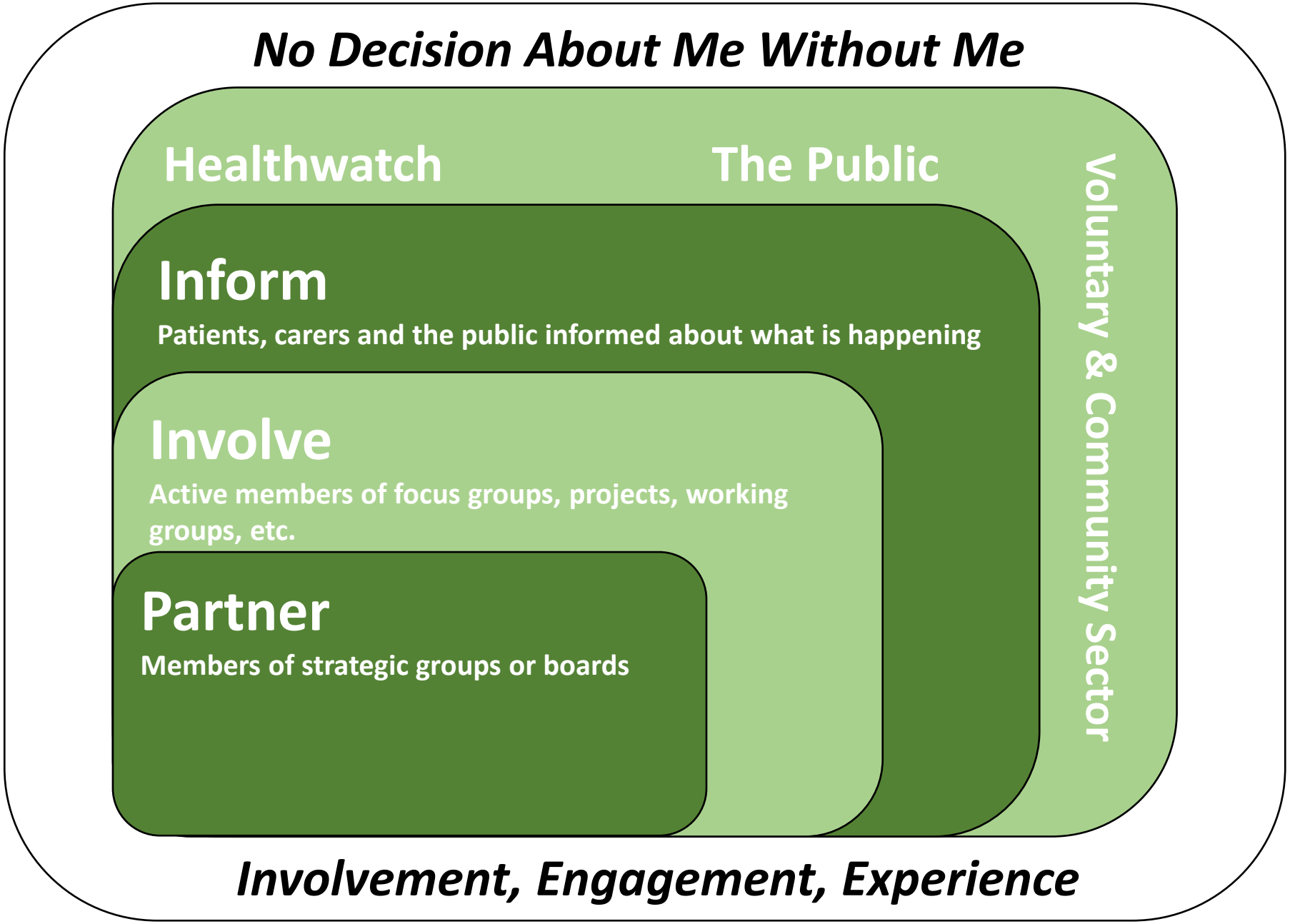
Involvement – ?

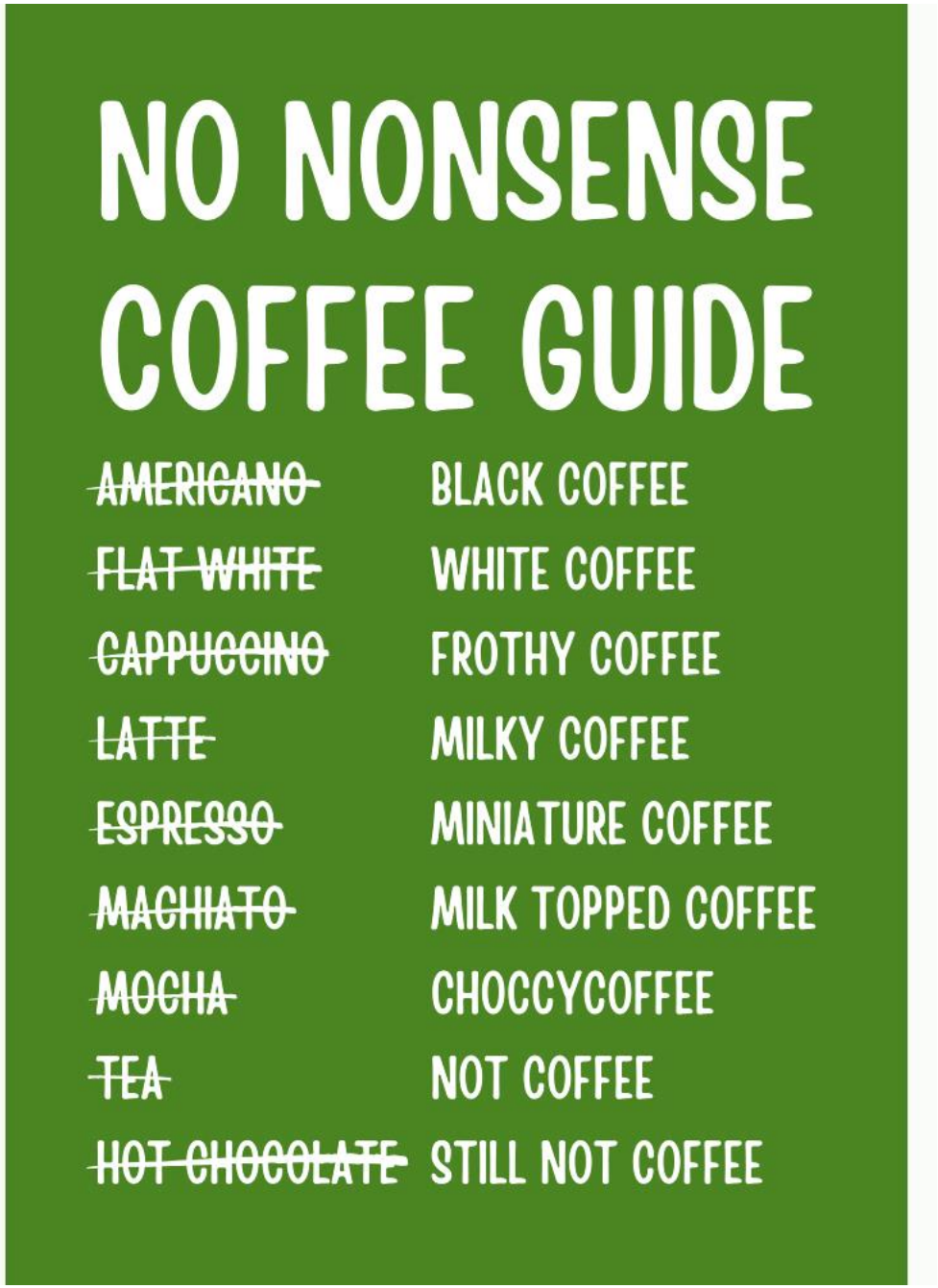


– a focus on **people**, em and **support** they need, fundam volving patients and the publi si ed for specific expertise


9
6

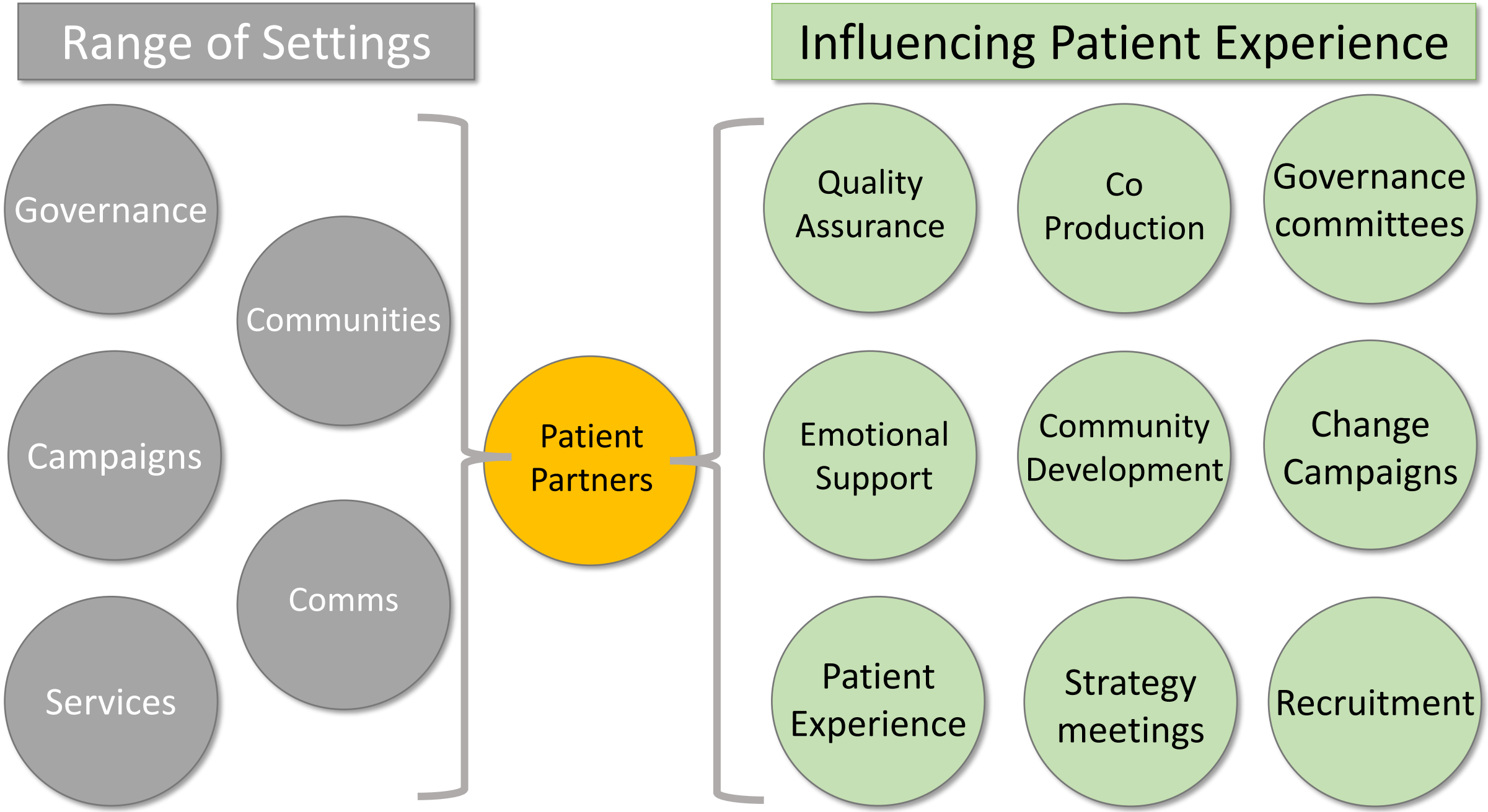

If you can't explain it simply, you don't understand it well enough.
– Albert Einstein

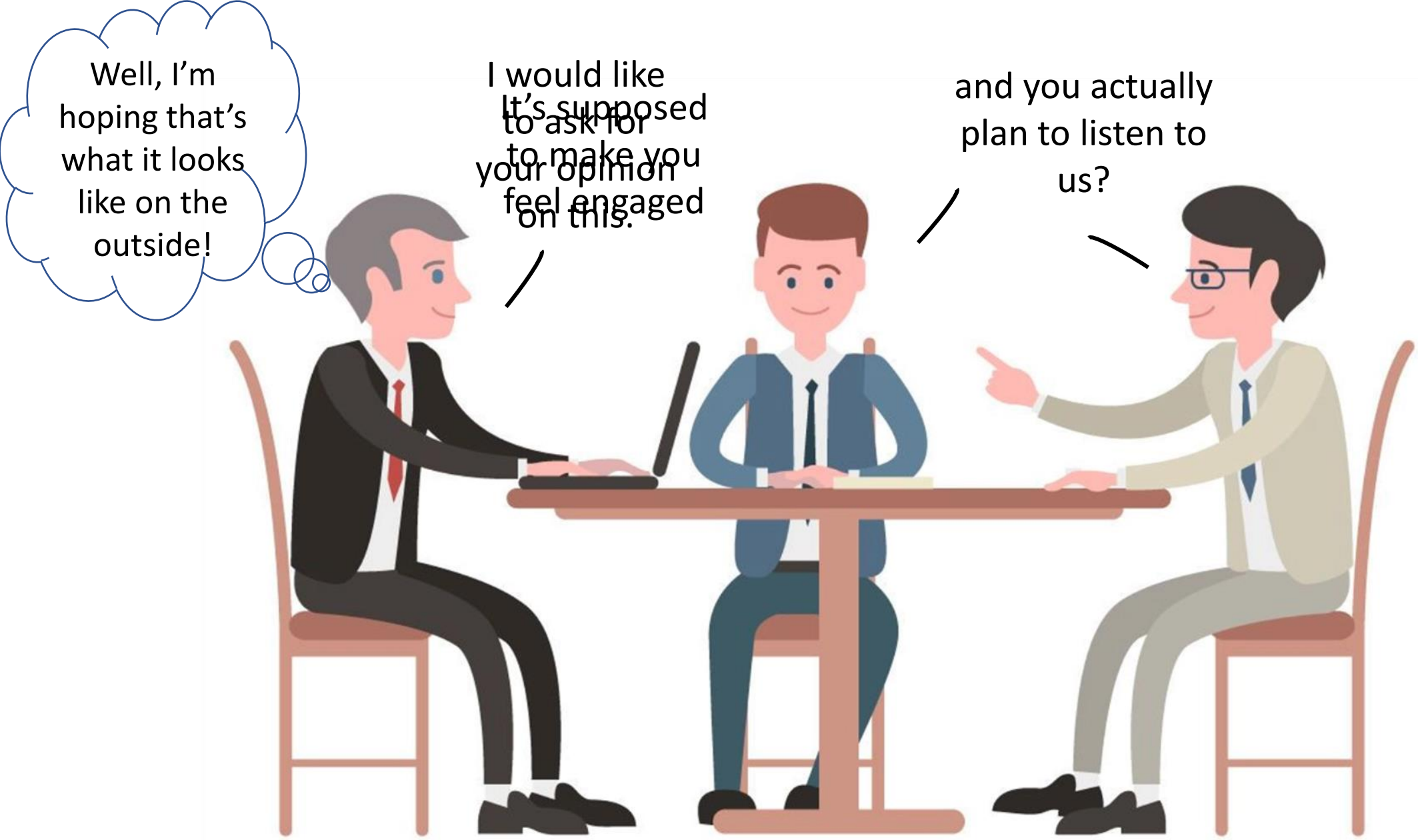

No Decision About Me Without Me
Healthwatch
The Public
Voluntary & Community Sector
Inform
Patients, carers and the public informed about what is happening
Involve
Active members of focus groups, projects, working groups, etc.
Partner
Members of strategic groups or boards
Involvement, Engagement, Experience



Co

- Define
- Design
- Deliver
- Decide
- Distribute
- Evaluate


Range of Settings
Governance
Communities
Campaigns
Comms
Services
Patient Partners
Influencing Patient Experience
Quality Assurance
Co Production
Governance committees
Emotional Support
Community Development
Change Campaigns
Patient Experience
Strategy meetings
Recruitment


Well, I’m hoping that’s what it looks like on the outside!
I would like to ask for your opinion on this.
It’s supposed to make you feel engaged
and you actually plan to listen to us?

Examples of Patients as partners

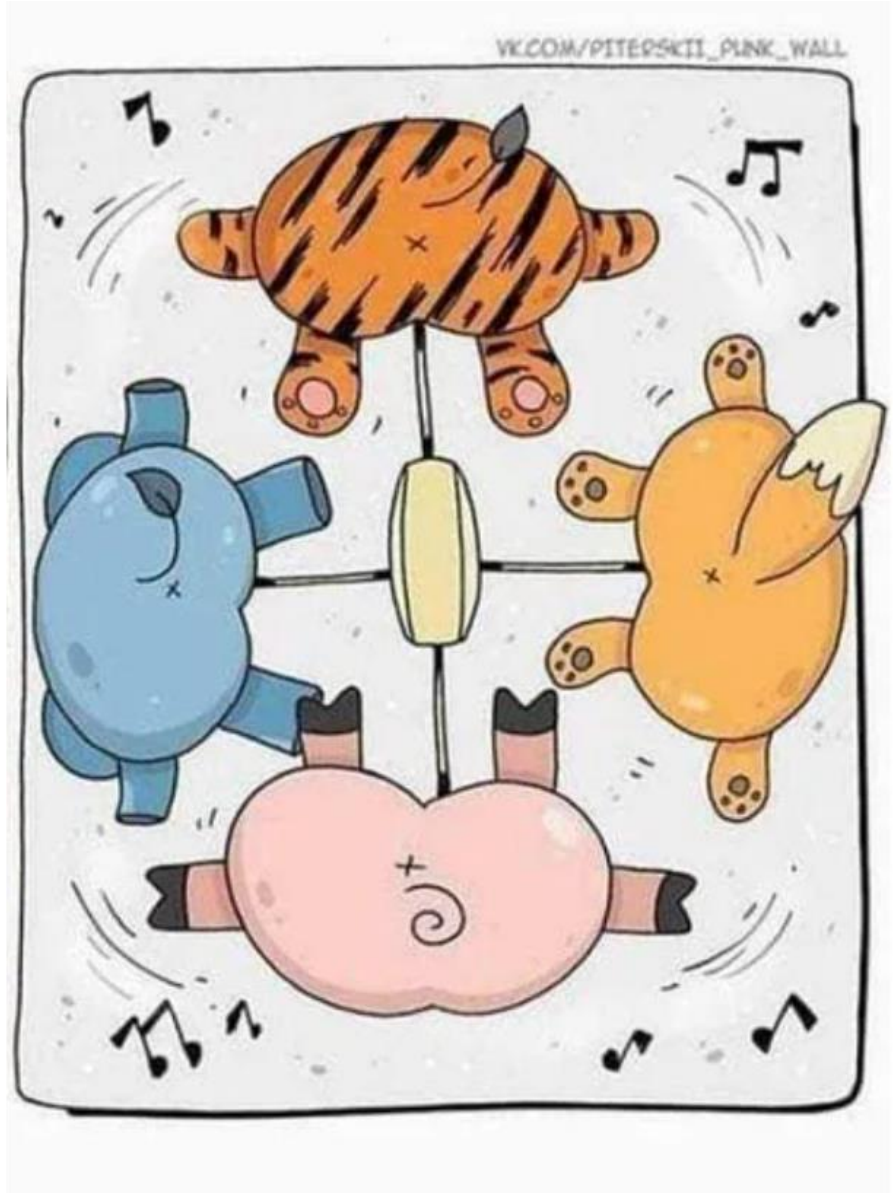
National 

- Patient Safety Partner
- Developing a PS Framework
- National ME group
- Interviewing
- Co producing patient education
- Communication

Local 

- PREMs in ortho
- PIFU in Prostate
- Improving together
- The stranded patient
- Improvement huddles
- Theatre Utilisation


I love it!
Me too!


VK.COM/PITERSKII_PUNK_WALL

Questions

bernhoven

Incorporating restorative just principles when engaging patients after adverse events

Caroline Heijckmann, MD PhD

Declaration of interest

None

Bernhoven, Uden (NL)

bernhoven

Bernhoven

Uden, the Netherlands

General hospital; 2000 employees; 280.000 people

- Internist-endocrinologist (2002)
- Medical leader quality & safety (2018)

- My ambition is to further improve the safety culture by collaborating with patients and healthcare professionals. Restore trust is a key element

Introduction

Restorative Just culture

- Serious adverse events are often accompanied by a lot of emotion
  - Not always enough attention for emotional healing of those involved
  - Open communication after an adverse event is difficult
- A more healing approach is necessary to help to restore trust
- In the literature this is called restorative just culture

Retributive Just culture

Where we come from

- Healthcare is safe when compliance with rules and procedures is guaranteed
- In case of an incident we do root cause analysis
- Then we add more rules and procedures

- Does this still make healthcare safer?

Restorative Just culture

Where we are moving to

- Everybody makes mistakes and healthcare is a complex system
- Invest in adaptability and resilience
- Learn by reflecting on daily practice
- Aim to repair trust and relationships

- Restore the system, rebuild trust and do whatever is needed to start the healing process of all involved

Retributive versus Restorative practice

Questions asked:

- Which rule is broken?
- How bad is that?
- What should be the consequences?

Taking responsibility in retrospect

Key components:

- rules and procedures as a starting point
- root cause analysis

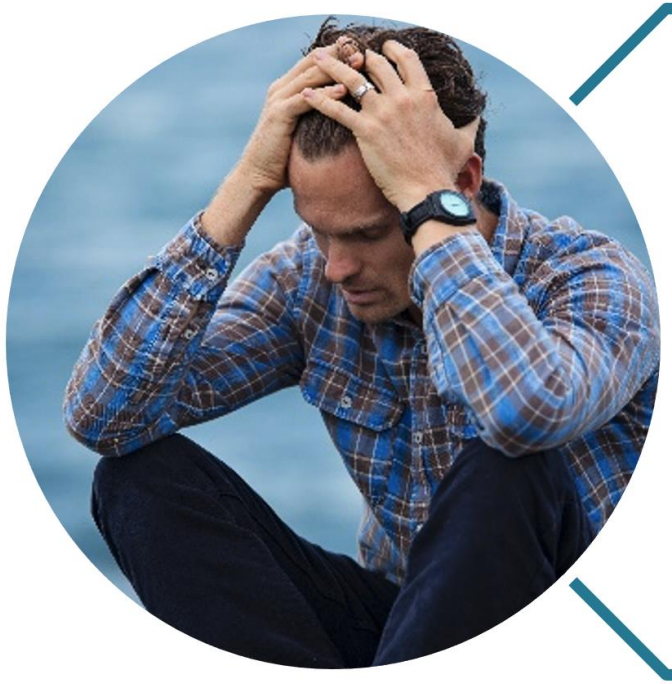
Questions asked:

- Who is hurt?
- What do they need?
- Whose obligation is it to meet these needs?

Forward looking accountability

Key components:

- emotional healing
- involvement
- trust
- learning



Key components:

- emotional healing
- involvement
- trust
- learning

The new approach

The new approach

Restorative Just Culture

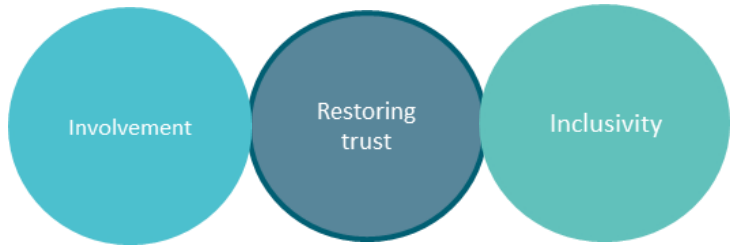
Who is hurt?
First victims: patients, family and relatives
Second victims: the care giver(s) involved in the incident
Organization and community: reputational damage

What do they need?
First victims: apology, information, restitution, reassurance, openness, compassion and psychological trauma care
Second victims: express remorse, peer support, compassion and reintegration
Organization and community: information, reputational repair, reassurance

Whose obligation is it to meet these needs?
It is important to coordinate this after an incident

Case 1

Muscle relaxant instead of pain medication during anesthesia



Case

- Male 55 years old
- Muscle relaxant instead of pain medication
- Paralysis including respiratory muscles
- Angry patient
- Reported to the Dutch Health Care Inspectorate

Approach

- Peer support for the healthcare professionals
- Case Manager contact on regular basis
- Trauma therapy for the patient
- Patient involved in incident investigation
- Collaboration in making a film about the incident
- The film is used for educational purposes

Learning to improve together

In this video, those involved tell about an serious adverse event
in the operating theatre caused by a medication error.

They share how they experienced this calamity.

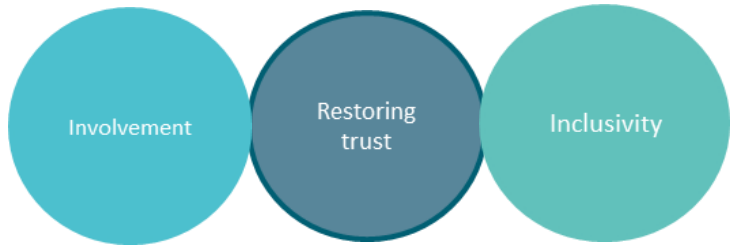
By doing so, we want to do justice to everyone's
own interpretation of the events.

We are very grateful to those involved for sharing their stories
so that others can learn from them.

7 July 2021, Bernhoven

Restorative Just Culture approach

results

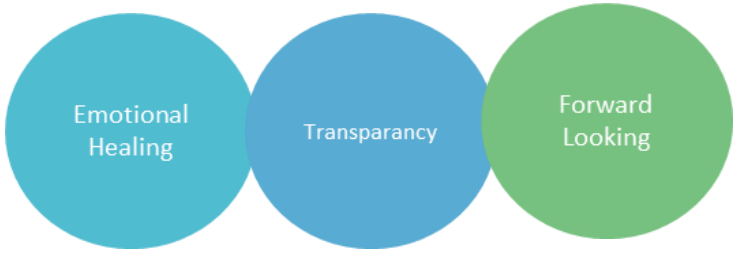


- From being angry to working together on improvements
- Restore trust (patient, healthcare professionals and inspectorate)

bernhoven

Case 2

Woman died after childbirth from pulmonary embolism



Case

- Woman 38 years
- Week before delivery she visited the ER two times because of physical complaints
- She died two days after giving birth to her 4th child as a result of pulmonary embolisms
- Family refused contact afterwards
- Emotional suffering by our healthcare providers
- Dutch inspectorate asked for reflection

Approach

- Peer support and trauma support for our healthcare professionals
- We have let the family know that we would always be willing to contact
- Family not involved in the incident investigation
- After 1,5 year the family contacted us
- We prepared a meeting

bernhoven

Restorative Just Culture Approach for our dialogue with this family

How did we prepare?

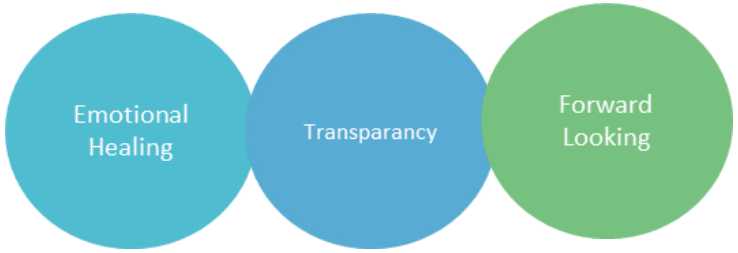
- We appointed an independent case manager
- We didn’t explain why things went the way they did! The focus was on their perspective
- We started with being thankful that they contacted us.
- We were empathetic and connected with the family.
- We kept an open attitude and invited them to ask whatever they wanted to know.
- We answered all their questions. Honestly and transparently
- We showed emotions
- We explained what has been learned

2 turning points in that meeting

- When her sister said that she imagined it would be difficult for us to tell when the pulmonary embolisms had occurred
- When the pulmonologist showed his emotions and pain

Restorative Just Culture approach

results



- **Family:** `despite the circumstances, they had a good feeling about the meeting. They experienced the conversation to be transparent, open, honest and empathetic. They found it helpful to be able to look the doctors in the eye and that has given them peace of mind. It helped them to restore emotionally'. They thanked us for our sincerity.'

- Contributed to emotional recovery of everyone involved

Lessons learned

Our lessons learned

- Case manager for the patient or family is essential
- Emotional recovery requires compassion, attention, time and energy
- Openness is only possible if we first pay attention to the emotions of those involved
- We can do more than just explain what went wrong
- Peer support alone is not enough
- You need a connection from person to person
- Every case differs so flexibility is needed
- Timing is important
- Communication skills / mediation skills are needed

bernhoven

Thank you for your attention. Questions?

c.heijckmann@bernhoven.nl