

# Rehabilitation – new paradigm

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# Introduction

- Not everything I say has evidence to support it (but most does)
- I do not necessarily believe or agree with everything I say
- Two stories

# Seminar

- Goal is to advise on how to **achieve best rehabilitation outcome for all people with disability** in Denmark
- Two parts (may not have time)
  - Organisation/management ideas
  - Role of evidence and guidelines
- Aim
  - Not discussing how to help one patient, **but**
  - Discussing how to help all patients

# Topic one

- To discuss four inter-related problems:
  - **Disabled people:**
    - Wait for or do not receive rehabilitation
    - Have less good outcomes than expected
  - **The state (or funders of care)**
    - Face increase in demand/need for care
      - Both numbers, and amount per person
      - At home, in residential care
    - Experience prolonged ‘unnecessary’ lengths of stay in hospital

# Content

- Talk through the issue in four steps:
  - Establish problems and cause(s)
  - Propose new way to consider the problem
  - Explore implications of new way
  - Suggest concrete actions to resolve problems

# Main message

- Need to move from:
  - Biomedical, disease-focused approach with
    - Rehabilitation as occasional add-one **after** medical process (i.e. in **series**)
- To:
  - Holistic, patient-centred approach with
    - Rehabilitation fully integrated with medical care at all times (i.e. in **parallel** )

# Is there a problem?

- UK figures suggest:
  - 2%-5% acute hospital beds 'blocked' by patients too disabled to discharge
  - Many patients have delayed transfer into separate specialist rehabilitation units
  - Many community-based disabled people do not receive rehabilitation
  - Outcome for patients is sub-optimal (stroke, MS etc)

# Cause

- Focus on disease to exclusion of all else
  - The 'biomedical model of illness'
    - Affects allocation of resources and attention
- And associated social view of patient's sick role:
  - Not responsible for disease
  - Passive recipient of treatment given
  - Excused from social duties
  - Expected to comply with treatments advised



# Effects

- Many including
  - Funding depends on disease diagnosis not disability needs
    - But care provided: ITU, nursing etc
  - Healthcare priority is disease services, not disability services
  - Disability services are separated from medical services
    - Even within a single organisation
  - Ignore functional/ psychological contribution to disability

# New paradigm

- Need to
  - Focus attention on the patient and their needs
    - Disability and distress, as **equal** to disease
- To do this need:
  - Better understanding of illness
    - An appropriate model
  - Better understanding of healthcare process
    - An appropriate model

# New models

- There are many (many!) models of illness
  - Will show one – the holistic, biopsychosocial model of illness
- There are perhaps no published models of healthcare processes
  - Will argue for a generic problem-solving model
    - Holistic = focused on disease and disability
      - Biomedical = focused on disease
      - Rehabilitation = focused on disability

**Four Levels** Holistic biopsychosocial illness model **Four Contexts**

Person in environment  
**Goal-directed behaviour**  
*Activities/disability*

**Objects**

Physical Context  
*Peri-personal*  
*More distant*

**T**

Organ (*pathology*)  
*Disease/diagnosis*

*Well-being*

**Person**

Body (*impairment*)  
*Symptoms/experiences*

*Choice*

Personal context:  
*Attitude, beliefs, etc*

**I**

**M**

**E**

Person in society  
**Social position**  
*Participation, social roles*

**People**

Social context:  
*Friends, colleagues*

# Being ill within biomedical model

★ Organ

*Disease (actual pathology)*

Whole body

*Symptoms & signs experienced*  
*Impairments of function implied*

Quality of life

Personal context

Temporal context

*experience, expectation, attitude, choice, belief, disease label*

Social context

*Expectations, attitudes, beliefs etc  
of others*

Participation

*Patient roles – sickness (expects help)*  
*Others' roles – sickness (gives help)*

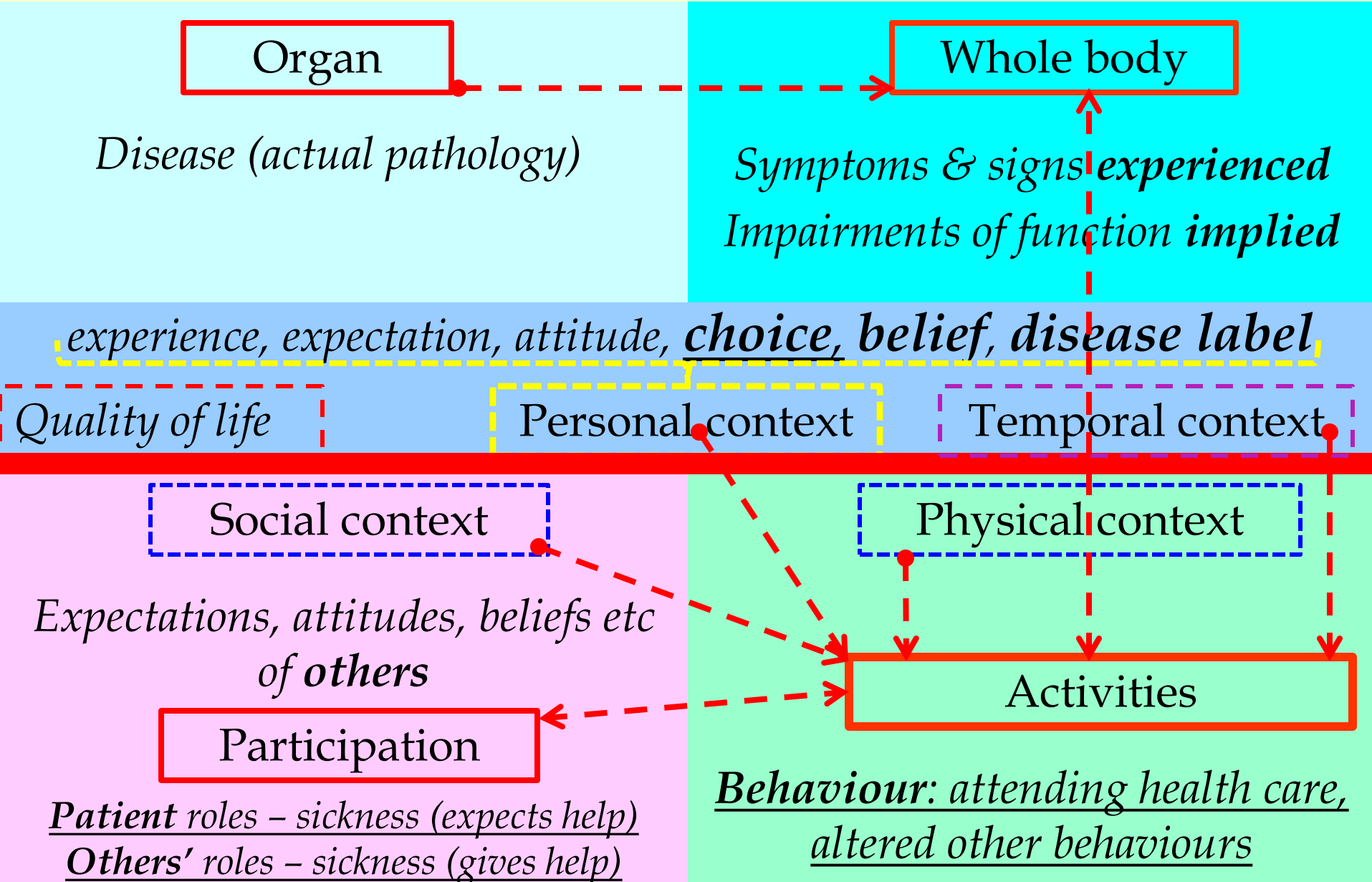
Physical context

*Objects, structures, bodies etc*

Activities

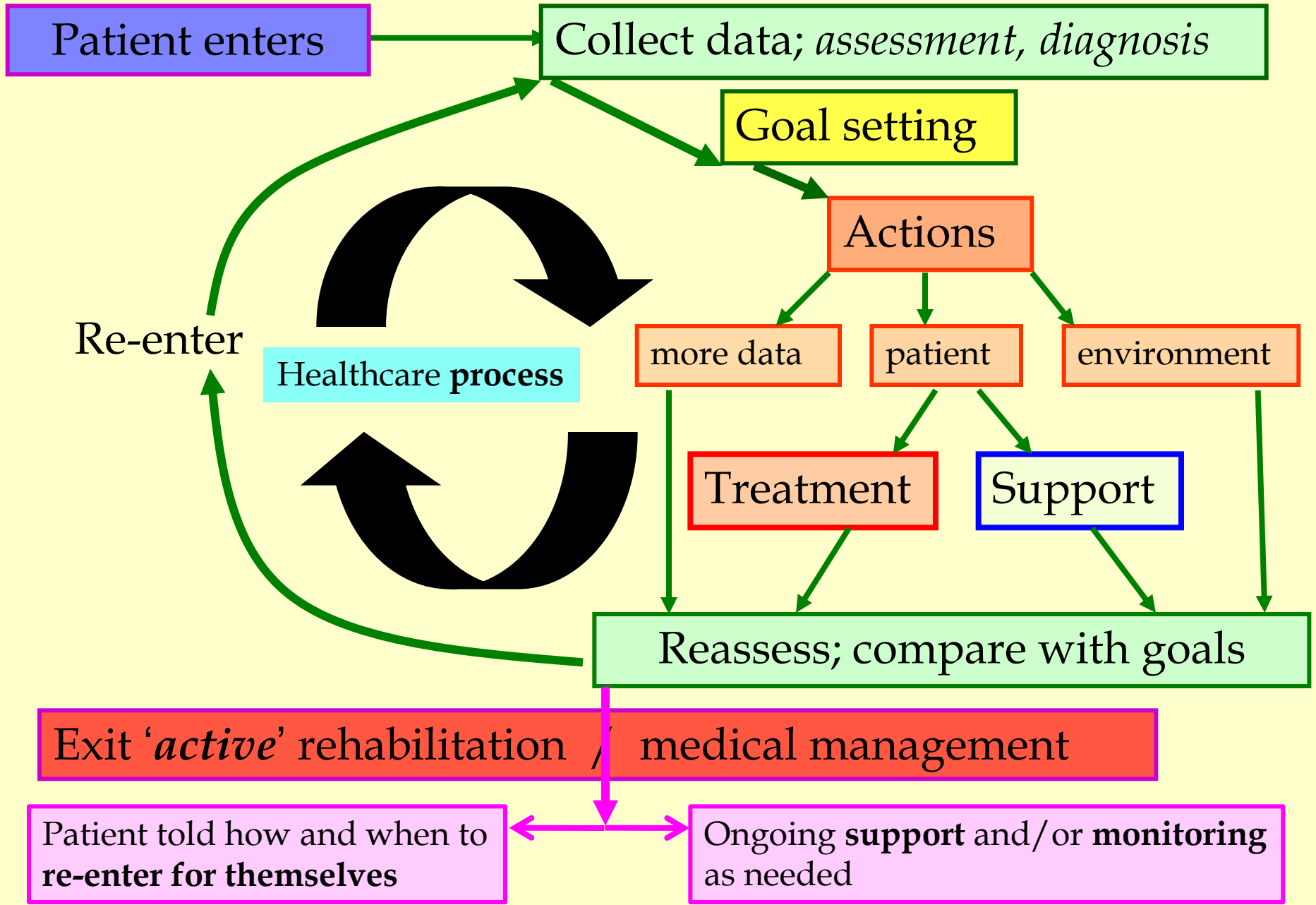
*Behaviour: attending health care,*  
*altered other behaviours*

# Being ill within biopsychosocial model



# Model of healthcare process

- Applies to
  - Disease (medical care)
  - Disability (rehabilitation)





# Rehabilitation implications

- Will consider consequences of this approach, comparing
  - Rehabilitation (disability-focus), **with**
  - Medical care (disease-focus)

# Implications - complexity

- Complexity more in rehabilitation
  - Many more factors involved
  - Spans many professions, organisations and settings
  - Most relationships are non-linear

# Implications - interventions

- To reduce disability
  - Act on patient **and** on context
  - Span settings, organisations, long time
- The primary processes are:
  - Communication and liaison (professionals)
  - Changing behaviour through teaching and learning (patient, carers), requiring:
    - Engagement/motivation
    - Practice with feedback

# Implications - time

- Rehabilitation needed at all times
  - Failure to practice causes
    - Loss of skill, and of confidence
    - Wasting of muscle
  - Evidence shows
    - Early mobilisation helps in hospital
    - Rehabilitation after discharge from hospital helps

# Implications – goal setting

- Multiplicity of causes and interventions requires:
  - Multi-disciplinary team to analyse & to treat
- Goal-setting meetings needed to:
  - Agree formulation of situation
  - Set goals to engage/motivate patient/team
  - Organise and co-ordinate multiple and/or complex actions

# Enacting new paradigm

- Need to consider:
  - Structure changes
  - Process changes
  - Measurement (outcome, resources)

# Structure – Rehabilitation team

- All patients in all settings at all times should have access to a suitably specialist rehabilitation MDT
  - All needed professions
  - One budget, management, place
  - Expertise in
    - disorders seen
    - assessment & formulation, goal setting

# Structure – physical context

- When not in own home setting
  - Need equipment and adaptations to allow patient to undertake activities
  - Requires carers/nurses to help practice
- Requires **major change** in hospital wards
  - Structure
  - Management culture (less risk averse; more nurse time)



# Structure – social context

Culture and knowledge and skills

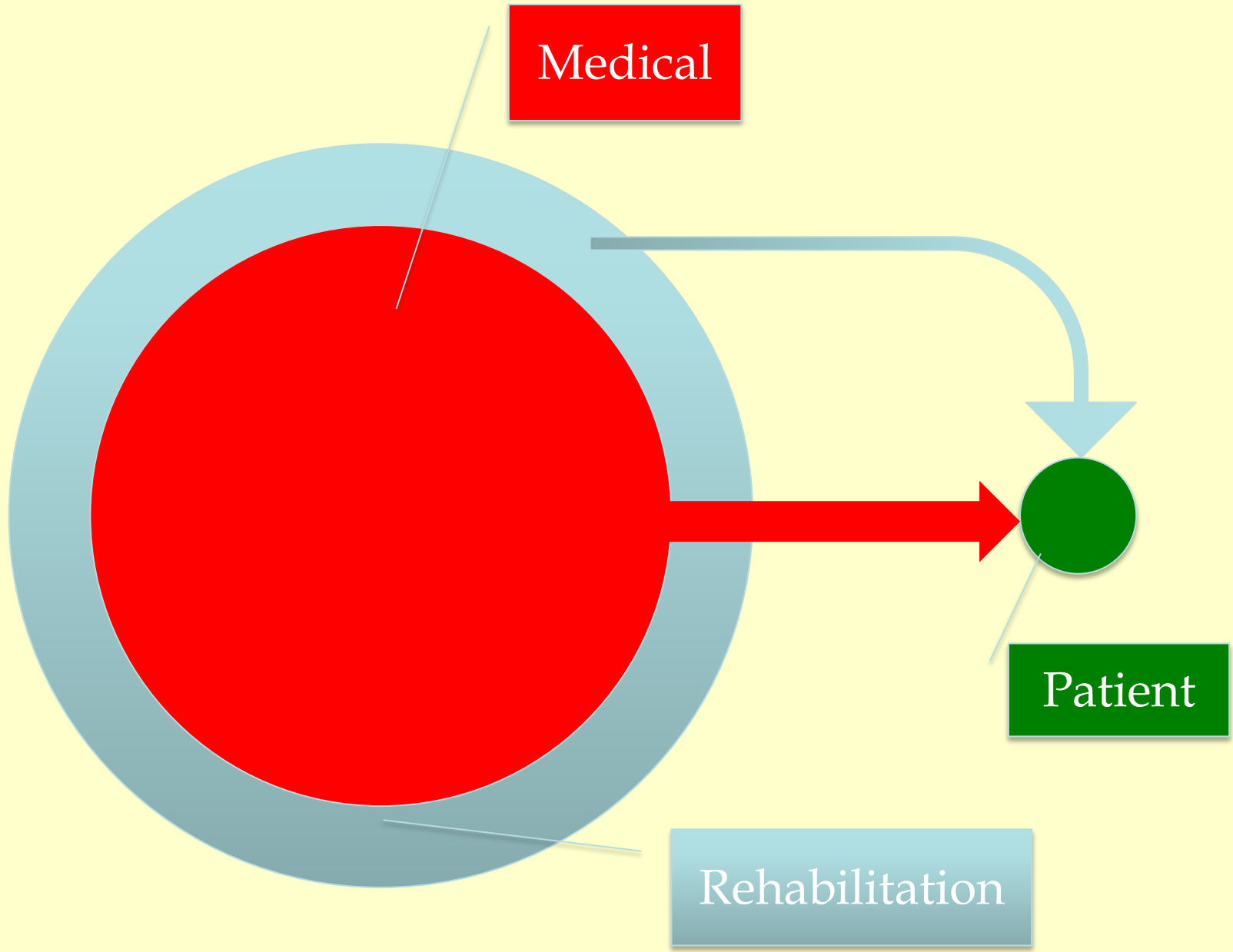
- Family and staff must allow practice
  - Avoid being risk adverse
  - Avoid helping because quicker/easier
  - Need teaching about what, how, when etc

# Process

- Rehabilitation team involved **in parallel** with medical team
  - From outset
  - Working collaboratively (meta-team)
- Patient-centred and evidence-based
  - **All care** (not just rehabilitation) adapted to patient's specific
    - Circumstances/situation
    - Wishes, expectations, values, goals

# Measurement

- Input (resources)
  - Structures available (including expertise etc)
  - All aspects of rehabilitation process
    - Not just face-to-face therapy time
  - Patient practice time
- Outcome
  - Disability and distress
    - Not disease

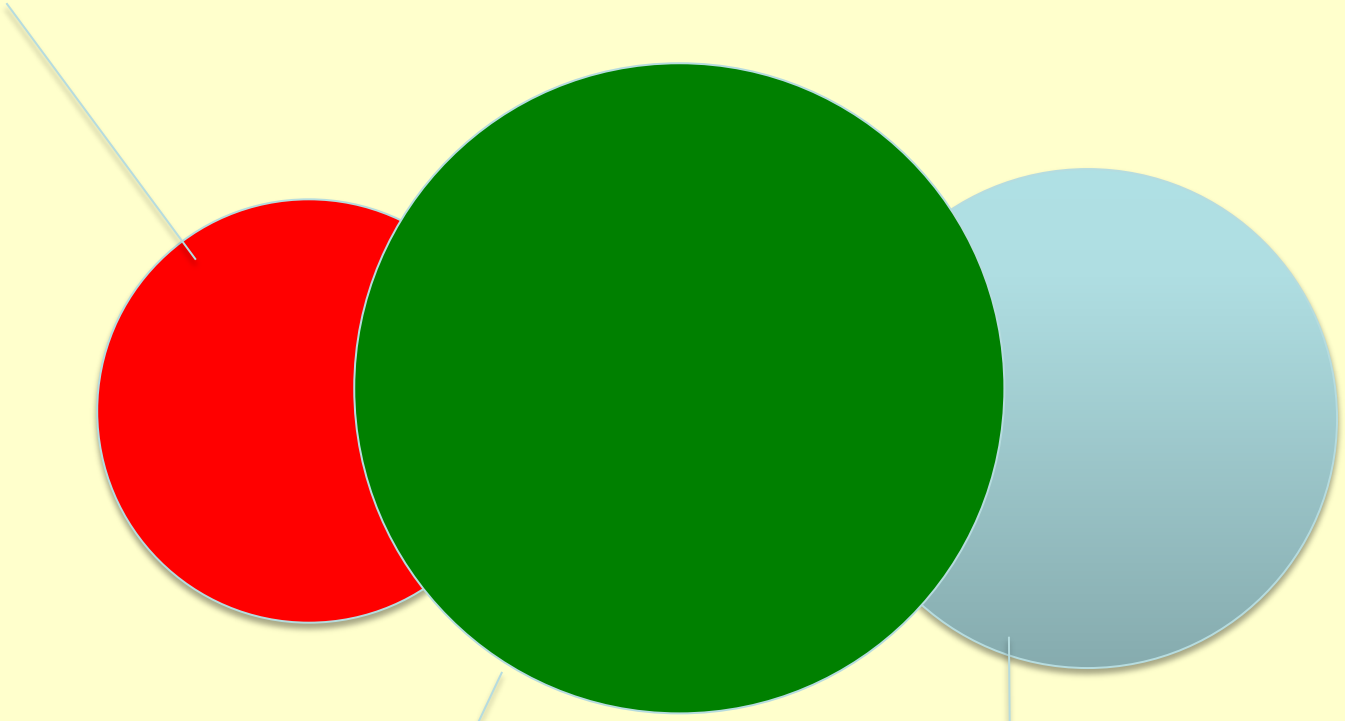


Medical

Rehabilitation

Patient

Medical



Patient

Rehabilitation

# Comment

- No direct, trial evidence of benefits but based on evidence:
  - Theories (e.g. learning and behaviour change)
  - Effectiveness of organised rehabilitation
  - Failure of all attempts to change within current biomedical model
  - Success of biopsychosocial model

# Comment

- Integration:
  - Reduces risk of being starved of resource
  - Disseminates knowledge and understanding of rehabilitation
  - Increases access to rehabilitation
- Risks:
  - Loss of identity - unlikely, still have team
  - Loss of expertise - unlikely

# Comment

- Separate speciality risks:
  - Isolation, with less understanding
  - Patients not being referred/seen
  - Starving of resource (mental health's experience)
  - Persistence of inappropriate model
- Benefits
  - ?research (not really)



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# Guidelines, evidence, patient

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# The problem

- How do I decide upon and undertake the best action(s) for my patient?
  - Use a guideline?
  - Review the relevant evidence myself?
  - Use my own experience?
  - Ask a colleague? (Use someone else's experience?)
  - Ask the patient?
  - Do what I have always done?
    - or what I was taught years ago?

# Content

- Discuss the rehabilitation context
  - Complexity – multiple factors
- Consider strengths and weaknesses of
  - Evidence (external knowledge)
  - Experience (personal knowledge)
  - Guidelines (external advice)
    - synthesised from external and personal knowledge)
- Nature of person-centred care
- Conclude that: ?

# The answer is:

- A model of evidence-based (rehabilitation) practice:
- It is possible, requiring
  - Theories, (e.g. of how/why treatments work)
  - Experienced, expert rehabilitation **teams**
    - Knowledge and skills covering range of problems seen
    - Critical analytic skills
    - Regular reviewing of practice and evidence

# Message

- Our actions are determined by our internal, implicit models
  - Theories of inter-relationships, cause-effect etc
- We need to move to more external, explicit models
  - Theories based on evidence (and tested against evidence)
- Theories are **meta-guidelines**

# Rehabilitation

- An educational and problem-solving **process**
- Based within the holistic biopsychosocial model of illness
- Focused on minimising disability
- (*aiming to:*
  - *Optimise social role functioning, and*
  - *Minimise distress, risk and discomfort*)

# Process of rehabilitation

- What is the situation?
  - Formulate, to understand problems, their causes and natural history of change
- What could be done and achieved?
- What should be done?
  - Patient preferences and goals
- Actions towards goals
- Review, and re-iterate cycle



# Analysis

- Use holistic, biopsychosocial model of illness to guide analysis and formulation

# Rehabilitation - main messages

- Problems are **complex**
  - **Non-linear interactions** between **multiple factors** across a range of domains, including
    - Patient's goals and choices/values/attitudes
- For one factor (e.g. spasticity)
  - Many factors influence it
  - It is associated with many other impairments
  - Consequences of changing it are unpredictable

# Evidence

- *“Ground for belief; testimony or facts tending to prove or disprove any conclusion.”*
- *“to have evidence to say, etc.: to have good grounds for saying, etc.” [OED]*

# Cause-effect evidence

- Must control for
  - Natural history
  - Variability within and between patients
- Therefore use RCT (and good single case study designs)
- Other designs invalid in determining cause and effect

# Evidence - limitations

- Usually only one intervention studied
  - Can be a complex intervention
    - **Often not well described** (cognitive rehabilitation)
  - Can investigate components
- Patients may be selected
  - Not representative of your patient group
- Unknown if
  - General response across many patients, or
  - Some patients respond well

# Study - cautions

- Bias in
  - Patient selection
  - Group allocation
  - Data collection and entry
  - Data analysis, presentation and interpretation
    - Subgroup analysis
  - Writing, and claims made
- Chance – often small numbers

# Systematic reviews

- Add strength to evidence
  - Meta-analysis
- Similar cautions and limitations
  - Bias and selection in the review process
  - Potential bias in populations included in original research

# Other evidence

- Testing out / developing theories
  - Associations and relationships
  - Predicting cause and effect that is confirmed
  - Utility – is it better than existing theory?
- Personal experience



# Evidence – personal experience

- Wealth of experience (data) accumulated
- Especially
  - Side-effects and adverse outcome
    - rarely reported in studies;
    - rarely seen in small studies
  - Effectiveness of locally provided treatments
    - Who can actually deliver (or fails to deliver)
- Always consider:
  - “*individual clinical expertise*” (personal data)

# “individual clinical expertise”

- Expertise is:
  - *Critical analysis* and use of all the data ‘collected’ personally (in memory etc)
  - Analytic and synthesising skills
- Expertise is **not**
  - Unsubstantiated *beliefs* with no data
  - Use of selected, biased personal data
  - What was taught or learned in past *unless* evidence supported it

# Evidence - main messages

- Validity of evidence depends upon
  - Population studied
  - Design and controls against bias
- Most studies should be replicated before being widely used
  - Dutch apraxia trial
  - TRACS
- Do not ignore own/team experience
  - **But consider it *critically***

# Guidelines – a solution?

- *“A guideline is a statement by which to determine a course of action. A guideline aims to streamline particular processes according to a set routine or sound practice. By definition, following a guideline is never mandatory. Guidelines are not binding and are not enforced.”*

<http://www.va.gov/trm/TRMGlossaryPage.asp>

- A general principle, rule, or piece of advice

# Guidelines - background

- Evidence incomplete
  - Have to use judgment, consensus etc
- Produced by humans with bias & beliefs
  - Influenced by commercial factors, personal experience, culture etc
    - Use protocols (e.g. AGREE) to minimise effect
    - But much is by consensus
  - Biased by use of hospital-based experts
    - Strong personalities
    - Unrepresentative experience

# Guideline after spinal injury

For Venous Thrombo-Embolism (DVT)

- *“Continue mechanical VTE prophylaxis until the patient no longer has significantly reduced mobility.”*
- *“Continue pharmacological VTE prophylaxis until the patient no longer has significantly reduced mobility.”*

# Guideline - process

- Usually sponsored/funded by someone
  - An expensive process
- Restricted scope common
  - E.g. “too difficult”, politically sensitive, resource implications
- Process rules over-ride common sense

# Guideline evidence

- Use
  - Primary evidence (e.g. RCTs)
  - Collated evidence (e.g. systematic reviews)
- Focus on interpretation/application
  - Should justify recommendation
- Restricted selection of evidence common
  - E.g. only spasticity after stroke for stroke guideline



# Guideline - focus

- Tend to focus on the treatment
  - Guideline for using intervention - how
- Not focused on the problem
  - Process of solving the problem – what, when
- Not given advice on pathways and protocols
  - Assessment
  - Choosing from a range of treatments

# Guideline - other limitations

- Lack of evidence, often because
  - Treatment not commercial (no funding)
  - Problem rare
  - Problem considered too difficult to research
- Usability limited
  - Number of guidelines – very many
  - Often not mutually consistent
  - Often large
- Soon out-of-date

# Guideline advantages

- Useful source of primary evidence
- Gives a starting point
  - Should only apply to 80% of instances
    - Not mandatory
- May also give
  - Alternative management
  - Process to resolve problem

# Guidelines - main messages

- Guidelines have major weaknesses
  - Limited relevance
  - Bias, incomplete, selective evidence
  - Variation between guidance given
- Guidelines may help
  - Initial idea on what and how
  - Source of evidence material

# Patient-centred care

- Two definitions
- My definition
- Consequences

Don Berwick, formerly of IHI, **defined patient-centered care** as: *“The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.”* [9]

[http://en.wikipedia.org/wiki/Patient-centered\\_care](http://en.wikipedia.org/wiki/Patient-centered_care)

9. Berwick, Don. ["What Patient-Centered Should Mean: Confessions of an Extremist". \*Health Affairs Web Exclusive\*. Retrieved 25 March 2011](#)

# Person-centred care

**Background:** Patient-centered decision making (PCDM) is the process of identifying clinically relevant, patient-specific circumstances and behaviors to formulate a contextually appropriate care plan.

**Conclusion:** Attention to patient needs and circumstances when planning care is associated with improved health care outcomes

Weiner SJ et al.

Patient-Centered Decision Making and Health Care Outcomes An Observational Study

*Ann Intern Med.* 2013;158:573-579.

# Patient-centred care

- Personalising advice and actions through
  - Establishing all potential interventions for all problems
  - Outlining options and associated outcomes
  - Respecting person's life goals, values etc
  - Negotiating agreed plan of action (and review time)
- Benefit = commitment & engagement



# Person-centred practice

- Establishes, understands and responds to person's (**not** *patient's*)
  - Superordinate, 'life' goals
  - Attitudes and preferences (risk/benefit balance, willingness to devote resource etc)
  - Specific choices

# Person-centred practice

- Looks at totality of problems and potential interventions to establish
  - Priorities in terms of effectiveness
  - Opportunities for dual effects/benefits from one intervention
  - Risks of dual effects/adverse effects
  - Organisational options
    - Order of intervention
    - Joint interventions

# Person-centred practice

- **Then** discusses the options with the person to outline
  - what **could** be done, and **then** to decide
  - What **should** be done
    - Who by, where and when, for how long etc

# Person-Centred Practice - main messages

- Person-Centred Practice depends upon:
  - Understanding of the person's perspective
  - Analysis of situation
  - Awareness of effective interventions
    - Evidence, and how and why they work
  - Awareness of local strengths & weaknesses
  - Ability to communicate and negotiate
- Sounds familiar?

# Evidence-based practice

- The way to achieve **effective** person centred care (**rehabilitation** and **medical care**) is to use the principles of **evidence-based medicine**

# What is Evidence Based Medicine?

*“Evidence-based medicine is*

- *the conscientious, explicit and judicious use*
- *of current best evidence*
- *in making decisions about the care of individual patients.*

*The practice of evidence-based medicine means*

- *integrating individual clinical expertise with*
- *the best available external clinical evidence from systematic research.”*

Centre for Evidence Based Medicine

# “best available external evidence”

*“By best available external clinical evidence we mean clinically relevant research, often from the basic sciences of medicine, but especially from patient centred clinical research into the accuracy and precision of diagnostic tests (including the clinical examination), the power of prognostic markers, and the efficacy and safety of therapeutic, rehabilitative, and preventive regimens.”*

Centre for Evidence Based Medicine

# Evidence-based practice

- Evidence should be used to guide all of:
  - Data collection (including person's goals etc)
  - Case formulation
  - Initial options for intervention
  - Negotiation with person
  - Delivery and monitoring of chosen actions



# Evidence - assessment

- Assessment is the collection **and** interpretation of data
  - Must be some goal
    - Problem, prognosis, select therapy, need etc
- Evidence may help in suggesting
  - likely problems to be found
  - Prior probability for screening tests
  - data-set needed (and best tool to collect)
  - factors to consider when using data

# Evidence - measurement

- Measurement is quantification of data against a metric
- Evidence may help
  - Select data-set needed (and best tool)
    - For purpose, stability, sensitivity etc
  - Interpret data

# Evidence - goals

- Goal setting may:
  - Motivate patient and team
  - Improve coordination, etc
- Evidence:
  - Helps identify potential goals
  - Suggests characteristics of good goals
  - Helps in use/interpretation of goal attainment

# Evidence - treatment

- Treatment – an intervention that leads to sustained change in ‘natural history’
- Evidence:
  - Informs on probability of benefit **and** harm
  - Guides specific actions in treatment (how)
    - *(Sometimes, if you are lucky!!!)*
  - Currently little on
    - **Content** of rehabilitation treatments
    - **Theoretical** basis of treatment

# Evidence, theory & logic

- Evidence forms basis of theories
  - Theories are tested against evidence
- Therefore basing decisions on sound, evidence-based theories is using evidence
- Theories allow application of principles (i.e. they are **meta-guidelines**)
  - E.g. infectious theory of disease and use of anti-biotics

# Argument against

- Each patient is unique:
  - In combination of pathology, impairments, contexts etc
    - True for all medicine (and science)
  - **Therefore** evidence not applicable???
- **NO** – invalid argument:
  - Group studies show likelihood of success
- Evidence gives the **probability** of benefit (or harm)

# Conclusions - evidence

- The basis of good clinical care is evidence
  - Used to inform all decisions and actions
- Not just 'direct evidence' (RCTs) but also:
  - Theories tested against and proven by evidence - meta-guidelines
  - Synthesised evidence - guidelines
  - Amalgamated evidence - systematic reviews and meta-analysis
  - Personal experience and local knowledge

# Conclusions – person-centred

- Person-centred care
  - Respects values and choices of person
  - Integrates person's goals and wishes
  - Considers totality of their problems (holistic)
- Person-centred care
  - Requires negotiation and planning
  - Improves outcome
- Is it cost-effective?





# Urgent need

- Development of sound, evidence-based and tested theories
  - Assessment including personal preferences
  - Goal setting and coordination
  - Improving activities directly
  - Selection and use of contextual changes (all)
  - Evaluation and monitoring
- Integration into all medical care

# Guidelines, evidence, patient

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