



Participatory research & evidence: researching adolescents with special health care needs

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Demand-driven care

- Ideal of citizenship
- Patients seen as health care consumers
- Patients and professionals should work together in partnership
- Patient participation a condition *sine qua non*
- Issue of patient participation is rarely discussed

Levels of patient participation in demand-driven health care

- *Micro level*: both active role of individual patients required (so that patients can be heard) and professional respect for the patient perspective (so that patients are being listened to)
- *Meso level*: involvement of patient organisations in policy making and priority setting in health care

Research into patient participation at the micro level: preferences and competencies

- Health care practice traditionally dominated by professional dominance
- Health care research reflects this hierarchy and professional framework (for example in terms such as ‘adherence to treatment regimens’)
- Research into patient preferences and competencies has low status and is not often done

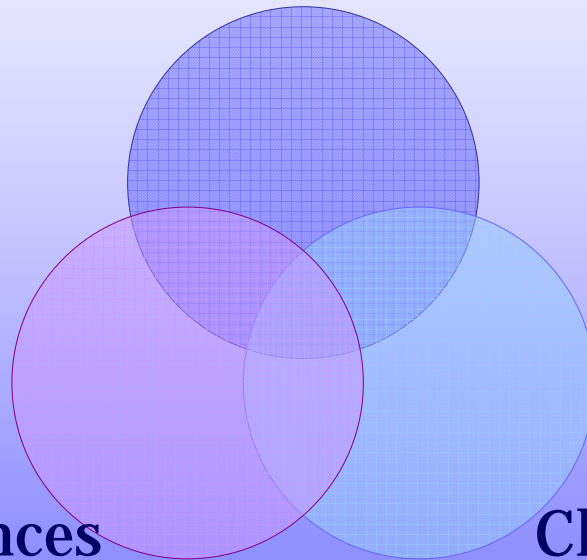
Definitions of Evidence-Based Practice

*"Process of systematically finding, appraising and using contemporaneous research findings as a basis for clinical decisions. **It aims to eliminate the use of expensive, ineffective and dangerous medical decision-making**"*
(Lockett, 1997)

*"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.***
(Sackett, 1996).

Model for evidence-based clinical decisions

Research evidence

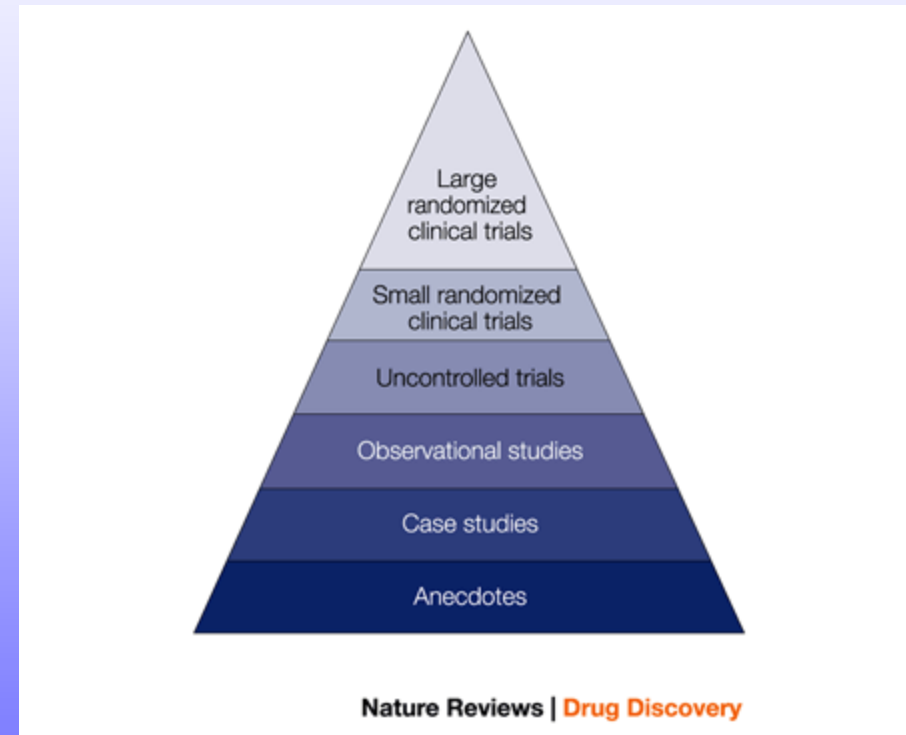


Patient preferences

Clinical expertise

What counts as evidence in EBP?

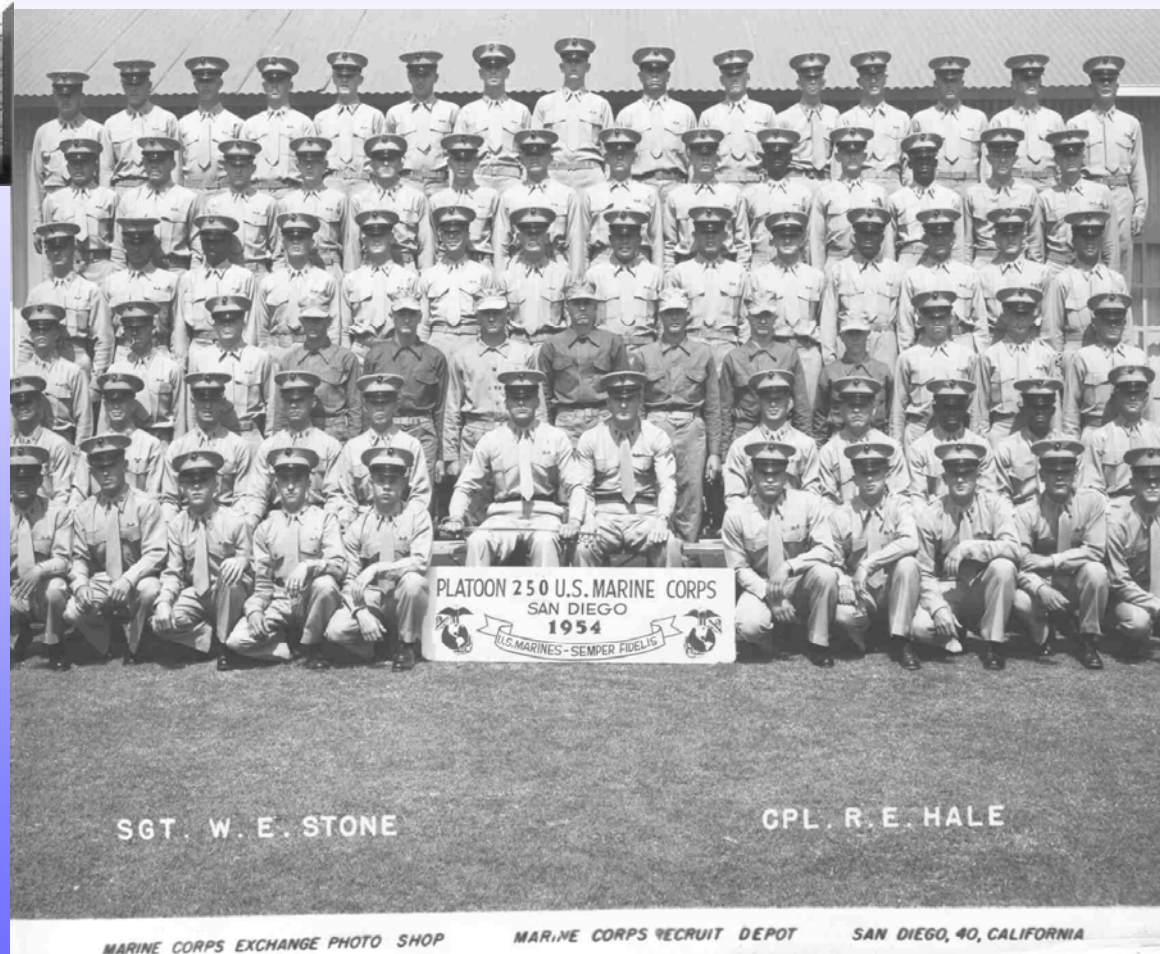
- Evidence is the result of rigorous, unbiased and systematic research
- Randomised Clinical Trial is the golden standard
- Hierarchy of evidence: RCT's rank highest; observational and case studies (incl. all qualitative methods) rank lowest



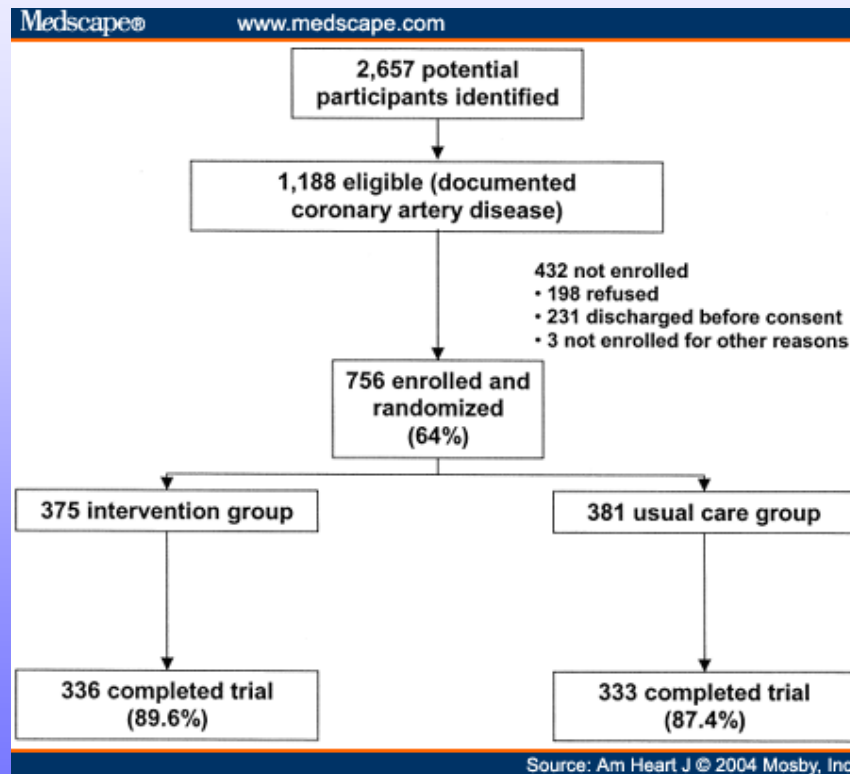
(Non) Patient participation in RCT's

- By choosing a randomized experimental research design, patient or professionals' preferences are excluded as much as possible
- EBP research agenda is concerned with efficacy of curative treatments or care interventions, not with patient preferences
- Even in determining relevant clinical outcomes for the research, the patient's perspective is often ignored

Patient recruitment for RCT's



selective participation and narrow inclusion criteria threaten external validity of RCT evidence



RCT as the golden standard for all health research?

1. For many important questions related to daily practice in health care RCT / CCT's are not the appropriate method
2. Important patient groups (f. ex. children) are routinely excluded from RCT's / CCT's; yet their inclusion is relevant to daily practice
3. In many situations in health research, it is unethical to deny patients influence over the treatment options (care interventions), selected design and outcomes

Choosing the best research design for each question

It's time to stop squabbling over the "best" methods

David L Sackett & John E Wennberg

Editorial *BMJ* 1997;315:1636 (20 December)

Our thesis is short: the question being asked determines the appropriate research architecture, strategy, and tactics to be used—not tradition, authority, experts, paradigms, or schools of thought.

*[...] And neither randomised trials nor non-experimental epidemiology are the best source of data on individuals' values and experiences in health care; **qualitative research is essential.***

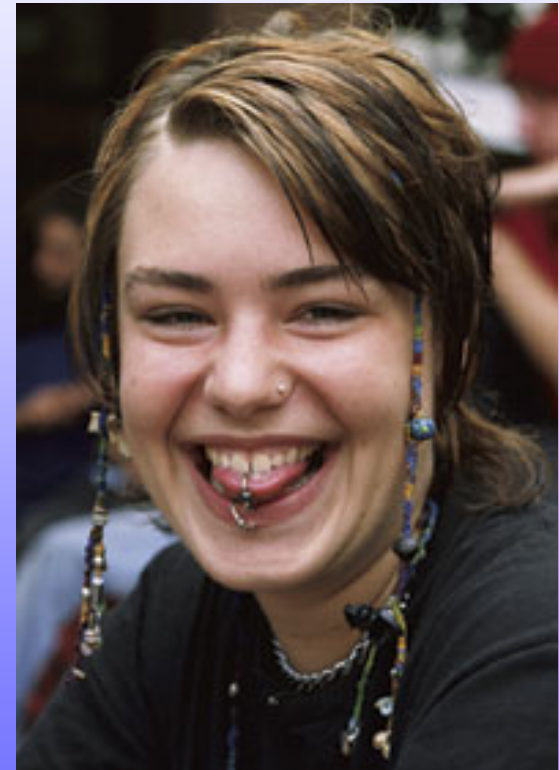
Growing up with chronic illness:

preparing for
transition to adulthood
& adult services



Children with special health care needs (SHCN)

- Those who have or are at increased risk for a chronic condition and who also require health and related services
- All young people with chronic illnesses and disabilities
- Adolescents: youth with SHCN between 12-19 years of age, still treated in paediatric setting



Problems reported with adolescents with SHCN by caregivers



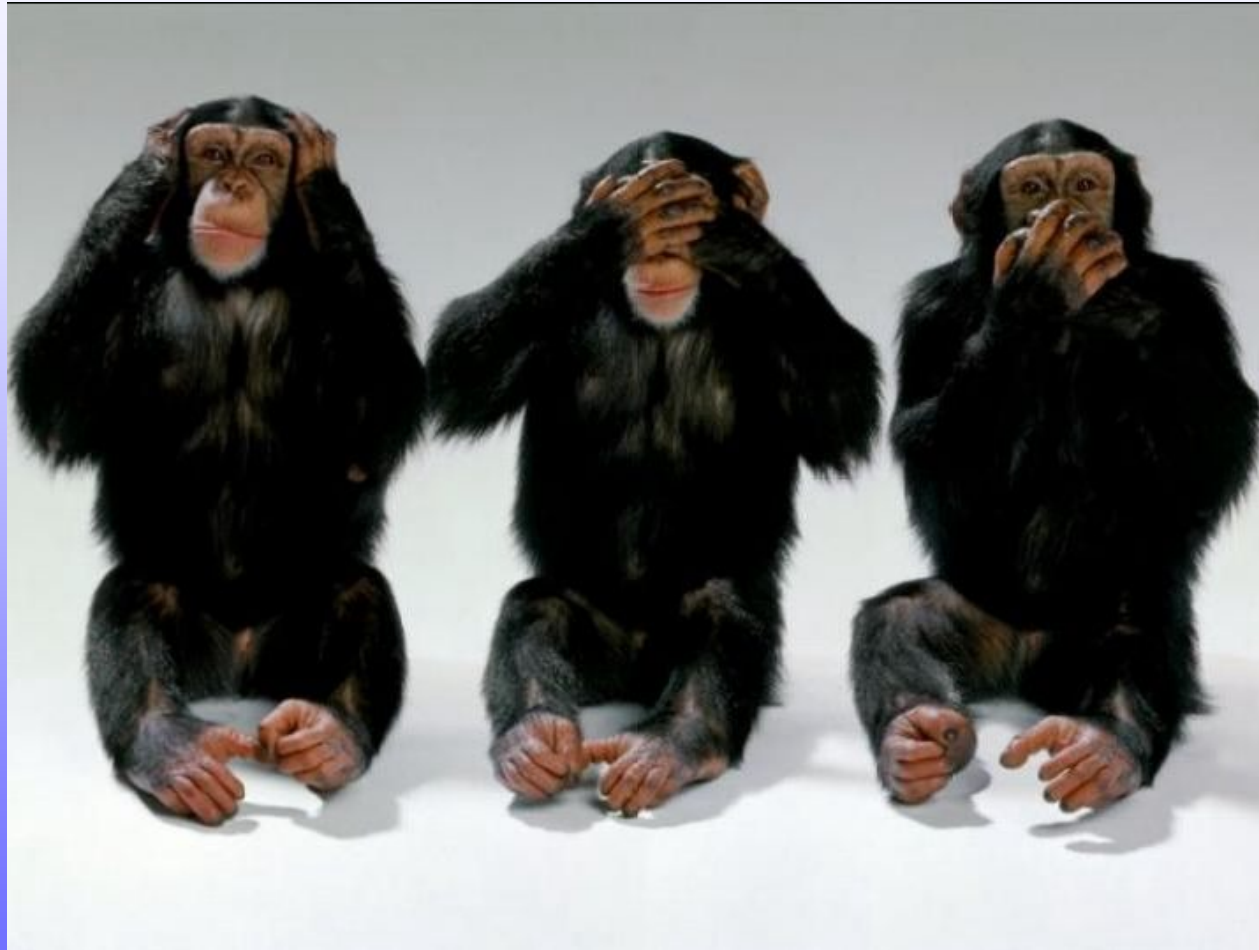
- lack of independence skills for self care
- drop-out of treatment schemes
- lack of compliance with treatment
- not motivated for healthy lifestyle
- involvement in risky behaviours

Adolescents: “orphans of the health care system”

Care for adolescents in paediatric hospitals and for young adults in adult settings is not well tailored to their developmental needs:

- Necessary competencies to function as adult in society and to function as an adult health care consumer are not being developed in a systematic way in the paediatric environment
- Planning of transition of care often inadequate, resulting in discontinuity of care

Children in health care: not seen, not listened to and silent





Participatory research project: On Your Own Feet



Research questions

1. What *preferences* do adolescents with chronic conditions hold with respect to the delivery of their care?
2. Which *competencies* of both adolescents and paediatric caregivers are important in preparing young people with chronic conditions for their transition to adulthood and to adult care?
3. To which extent are these competencies present in the *actual practice of care* and how should these competencies be developed in a systematic way in order to prepare young people for their transition of care?



Research design

- Participatory approach: active involvement of target groups (adolescents SHCN; nursing specialists and students) as co-researchers
- Various *qualitative methods* (triangulation) in three stages:
 - Interviews, questionnaires, Q-methodology, focus groups with adolescents with SHCN
 - Participant observation of interaction during consultations (adolescents, care givers)
 - Interactive group sessions with adolescents, care givers
- *Quantitative method*: web-based questionnaire

Why participatory research with children and adolescents?

- Children should be seen as social actors, capable of reflexivity about their own situation
- Child participation in decisions which affect them in everyday life is a fundamental citizens' right
- Participation is appropriate from educational viewpoint: learning to take responsibility and to speak out
- Giving adolescents a voice means taking them seriously. Good health care practice involves patients actively, the same applies to social research

Possible advantages of participatory health research

- *A view from within*: what it is like and what it takes to grow up as a young person with SHCN, in their own words
- *Learning* from young patients how care can be improved from their perspective
- Involving young people and caregivers in a *dialogue*, as to improve mutual understanding and establish more effective communication
- Participation in practice-oriented research enhances *commitment* to implementation of results by professionals and patients

Possible disadvantages of participatory health research

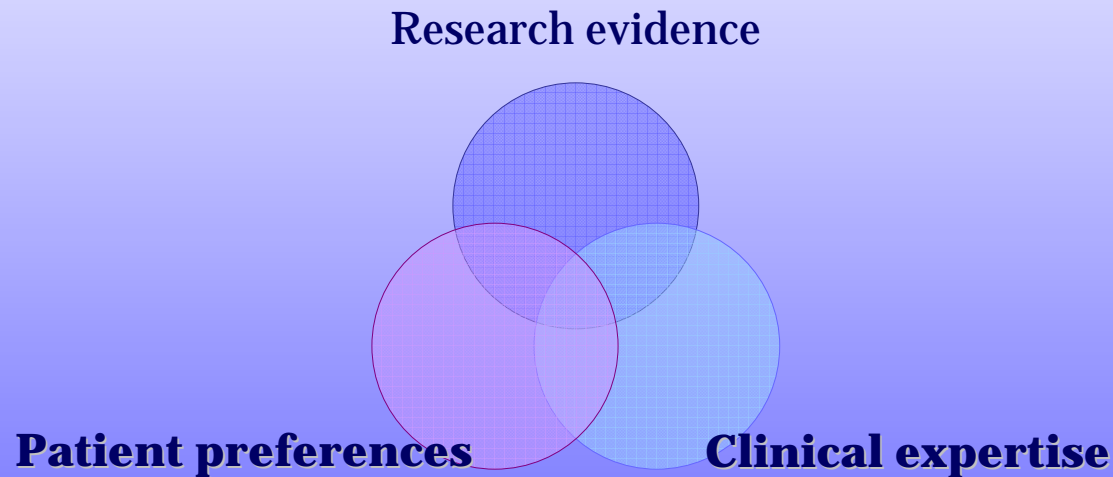
- *Selection bias*: adolescents who participate are not comparable to those who do not: to what extent can the results be generalised?
- *Research process* itself is more complicated: gaining access, passing adult gatekeepers, ensuring and maintaining participation of young people
- Researchers do not *control* the research process and are dependent upon co-researchers, risk of failure, need for quality assurance

How strong is evidence from participatory research compared to non-participatory research?

- Stronger in generating practice-oriented information such as patient preferences and competencies
- Stronger in identifying solutions / effective interventions in real life
- Stronger in generating enthusiasm and commitment for research & implementation
- Stronger in patient friendliness & educational potential
- Fits the demand-driven care discourse
- Weaker in precision and measuring the effect in numbers
- Weaker in external validity, as there is an obvious difference between those who participate and those who do not
- Weaker in convincing die-hards who only believe in statistics
- Weaker in researcher friendliness
- Does not comply with Hierarchy of Evidence model

To improve health care practice, we do not only need evidence on interventions, but also on patient / professional preferences & experiences

A participatory approach may hold important advantages over non-participatory research



Thank you!



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