

Evidence-based participatory disability research

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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.

...thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care. 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.

- Source: 'Evidence based medicine: what it is and what it isn't' -- Sackett et al. 312 (7023): 71 -- BMJ

Evidence hierarchy (Source: SCIRE)

Level	Research Design	Description
Level 1	Randomized controlled trial (RCT)	Randomized controlled trial, PEDro score ≥ 6 . Includes within subjects comparison with randomized conditions and crossover designs.
Level 2	RCT	Randomized controlled trial, PEDro score < 6 .
	Prospective controlled trial	Prospective controlled trial (not randomized).
	Cohort	Prospective longitudinal study using at least 2 similar groups with one exposed to a particular condition.
Level 3	Case control	A retrospective study comparing conditions, including historical controls.
Level 4	Pre-post	A prospective trial with a baseline measure, intervention, and a post-test using a single group of subjects.
	Post-test	A prospective post-test with two or more groups – intervention, then post-test (no pre-test or baseline measurement) using a single group of subjects.
	Case series	A retrospective study usually collecting variables from a chart review.
Level 5	Observational	Study using cross-sectional analysis to interpret relations.
	Clinical Consensus	Expert opinion without explicit critical appraisal, or based on physiology, biomechanics or “first principals”.
	Case Report	Pre-post or case series involving one subject.

“by its own criteria experimentalism only works when the world is linear and when causes are simple and single” (Byrne, 1998, p. 65)

UK Medical Research Council: Evidence production cycle

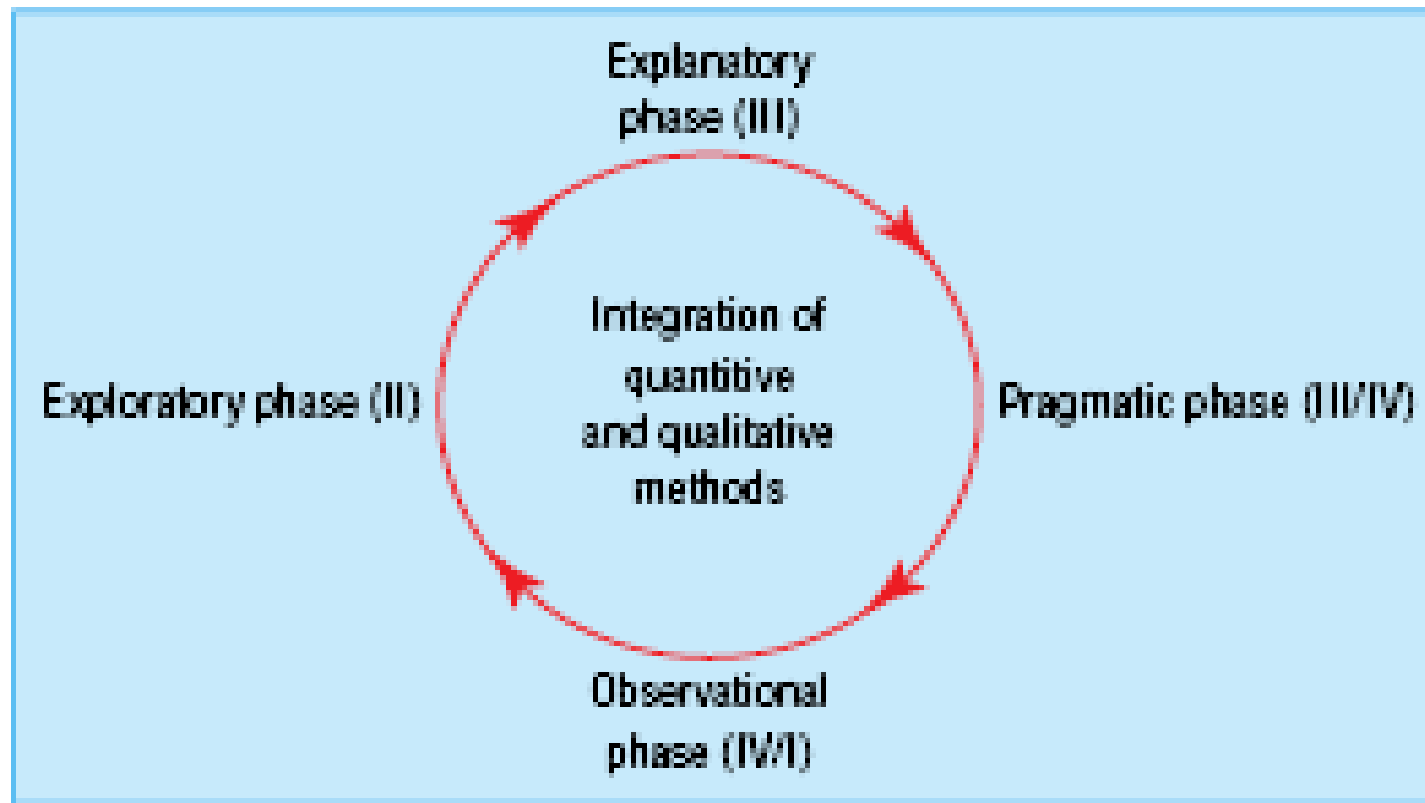


Fig 2 Iterative view of development of randomised controlled trials of complex interventions

Campbell et al. BMJ 2007

Exclusion at two levels

- As essential agents: Agenda setting, project planning, delivery, interpretation and dissemination
- As essential beneficiaries: Study designs, settings, methodologies don't allow for participation
- Probably a false dichotomy?

Who is excluded from research?

People with Disabilities

- Physical (Mobility Impairment): Example: “Cannot write answer” (without accommodation)
- Sensory (Vision, Hearing, Speech): Example: “Cannot read question” (without accommodation)
- Cognitive (Attention, Memory, Concentration, Learning): Example: “Cannot remember question”; “Cannot understand question” (without accommodation)
- Psychiatric (Depression, Psychosis): Example: “Does not trust interviewer” (without accommodation)

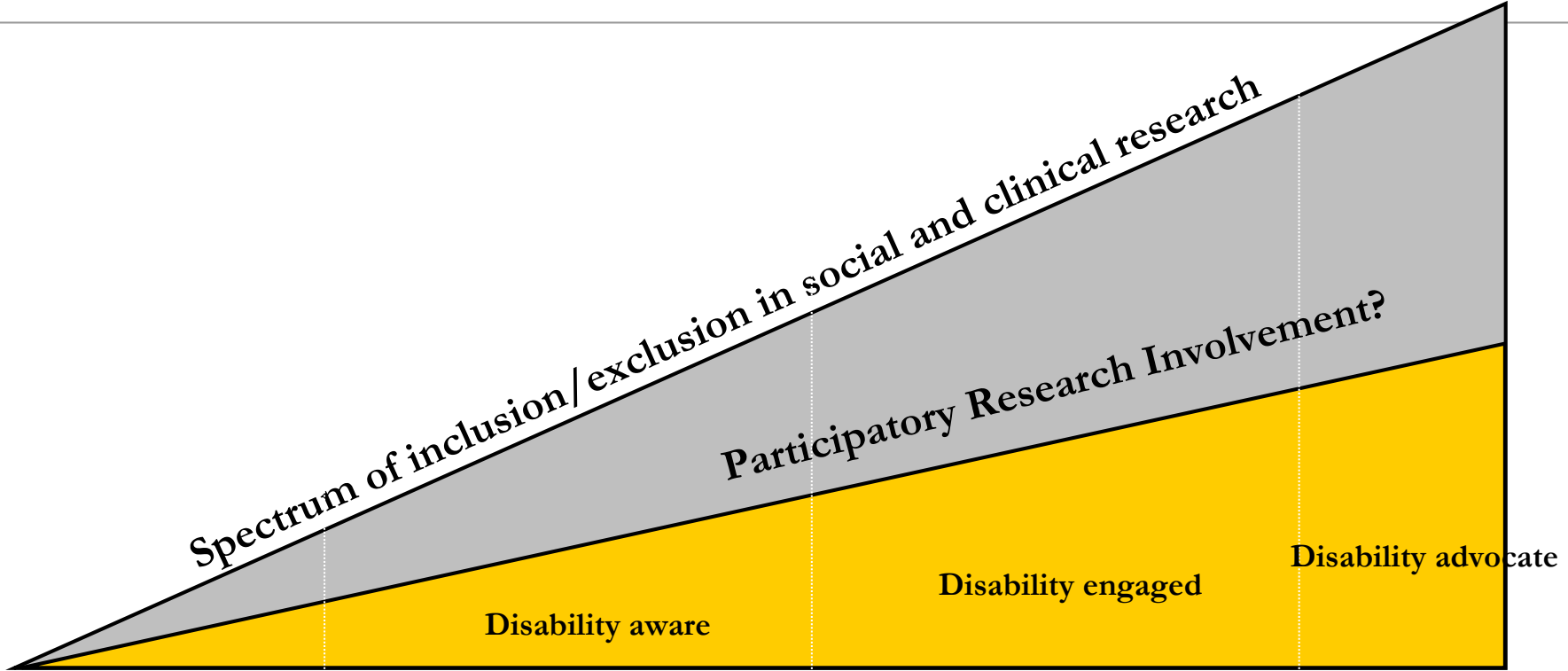
Who is excluded (continued)?

People from / with

Socially marginalized groups (e.g. income, education, living conditions) Example: “Homeless adult with diabetes-related disability and limited formal education lives in shelter 2 out of 7 nights”

Ethnic and linguistic minorities (e.g. Spanish speaking adults with cognitive or speech impairments)

Multiple social disadvantage



Invisible

Multiple
modifications to
“standard” data
collection practices
needed

Simple modifications to
“standard” data
collection practices
needed

No
Modifications
needed

(Some) reasons for exclusion

- Designs, data collection not flexible enough to be customizable to specific respondent needs
- People do not conform with ‘inclusion’
- People cannot be found or researchers don’t look
- Researchers/interviewers not sufficiently trained
- Time/funding constraints
- Lack of funds for alternative formats

Patients were **excluded** if they: (1) were not returning to their GPs for management, (2) were discharged to a nursing home, (3) had serious comorbidities, (4) were non-English-speaking, (5) died while in hospital, (6) were too cognitively impaired, (7) were notably aphasic or (8) lived more than 2 h away by car or (9) suffered from subarachnoid haemorrhage or subdural haematoma. Other reasons for non-participation included the family declining to take part, involvement in another research programme and not being assessed prior to discharge. p 280

Integrated care improves risk-factor modification after stroke: initial results of the Integrated Care for the Reduction of Secondary Stroke model

Two principal consequences of exclusion

- personal: **health and safety** risks (research findings, interventions based on biased assumptions)
- societal level: flawed statistical basis for decision-making and **resource allocation**

Participation as a remit in the health service (e.g. England)

“The UK policy of actively encouraging consumers to engage with researchers has its basis in prevailing notions of accountability rather than evidence-based practice. User involvement has become established in service development and audit in order to facilitate a more democratic and open provision of service delivery...The concept has been extended into the area of health research, and is beginning to be accepted by NHS (National Health Service) trusts...(Boote, Telford & Cooper, 2002, p. 214)”

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*Patient and Public
Involvement in Health:*

The Evidence for Policy Implementation

A summary of the results of the
Health in Partnership research programme

Defining and conceptualising P(A)R

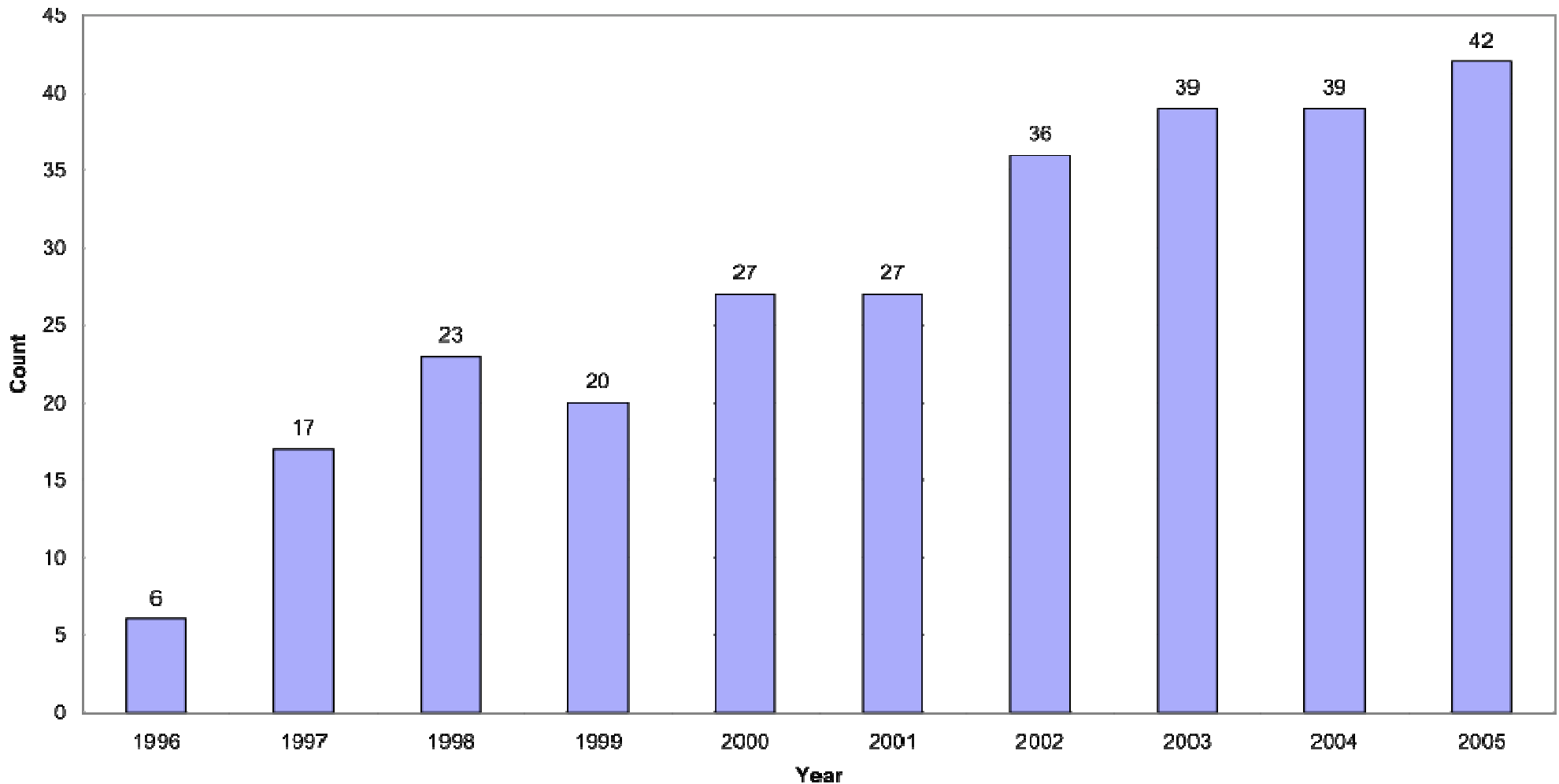
- Recent Evidence Report (AHRQ): Community-based Participatory Research: Assessing the Evidence (Viswanathan et al., 2004)
- (Community based) participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organisations, and researchers in all aspects of the research process to improve health and well being through taking action including social change (p. 3)

Trends in PR with People with Disabilities: Publications in the scientific literature between 1995-1996

- Increasing number of publication since 1996 refer to service user participation in research with people with disabilities

PR publication trends related to disability

PR Publications 1996-2005



Multiple electronic databases, including AMED (Allied and Complementary Medicine, 1985 to May 2006); BNI (1985 to May 2006); CINAHL, 1982 to May Week 4 2006); EMBASE, 1996 to 2006 Week 21); Ovid MEDLINE(R), (1996 to May Week 3 2006); PsycINFO (1985 to May Week 4 2006) and Social Work Abstracts (1977 to March 2005)

Searching for P(A)R evidence

- Recent Evidence Report (AHRQ): Community-based Participatory Research: Assessing the Evidence (Viswanathan et al., 2004)
- N=185 papers (55 – definitions; 123 – quality; effectiveness; 7 grant proposal review criteria)

Findings: Study designs

- 30/60 studies were intervention studies (organised and planned effort to change individual behavior, community norms, practices or policies)
- 12/30 evaluated intervention (18 not completed intervention or evaluated fully)
- 4/12 randomised controlled trials (RCT), 5/12 quasi-experimental 3/12 non-experimental

Findings: Community involvement

- 16/60 documented community involvement
- 28 (60) involved community to set priorities
- Community involvement mainly in the role of advisory panels (true PAR?), researchers taking lead role
- 19/60 shared funding
- 28/60 active participation in study design and implementation
- 3/60 demonstrated policy changes in civic bodies
- 5/60 change in private institutions or at local levels
- 13/60 reported sustainability
- 28/60 changes in health or other aspects of daily life

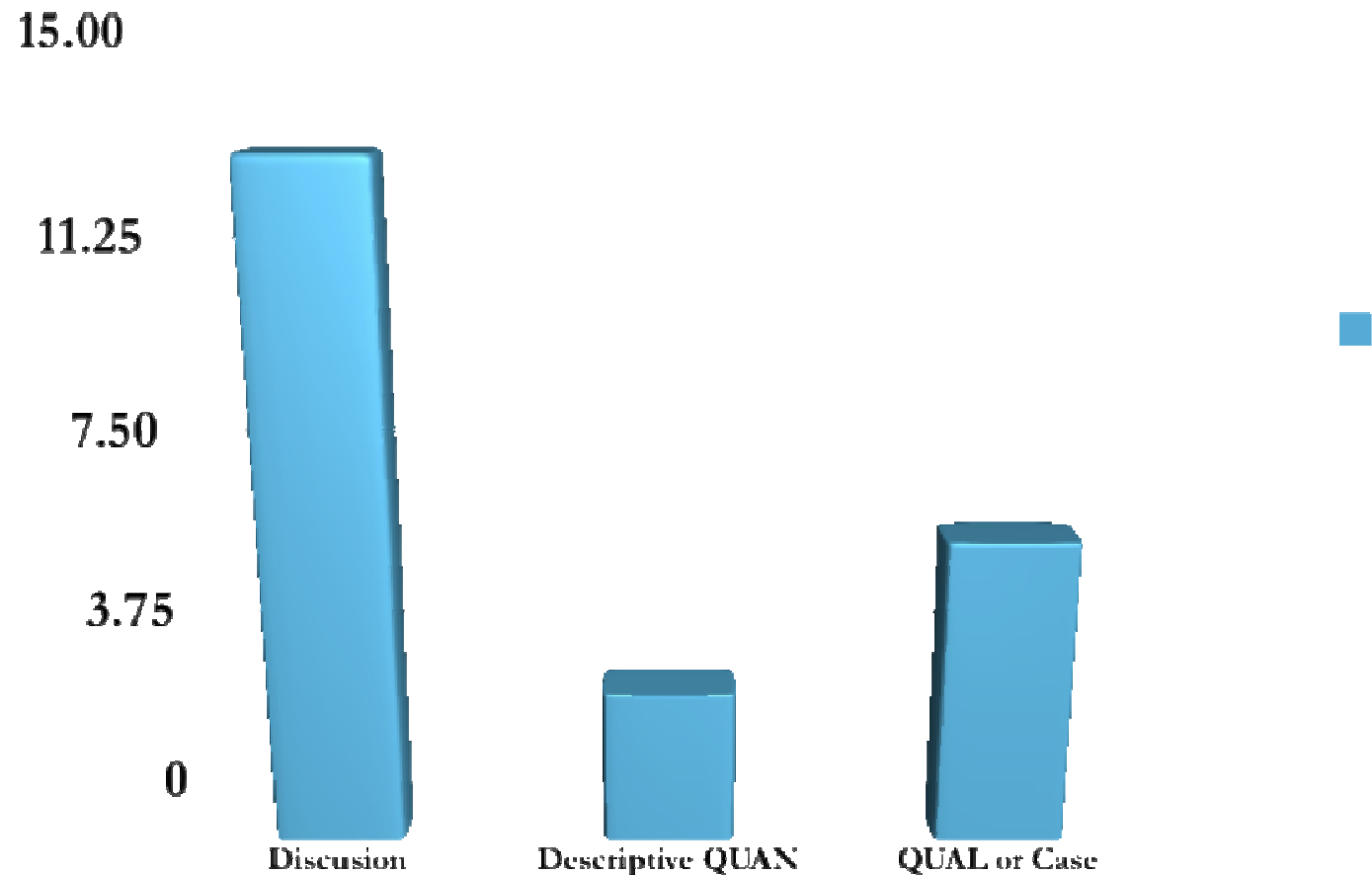
Findings: Outcomes

- 47/60 reported increased community research capacity as a result of the study
- 12/60 reported completed interventions (heterogeneous health outcomes) – not sufficient evidence
- 12/60 studies rated (1-3 scale) for research quality (M=2.3, min=1.5; max=2.8) and for community participation quality (M=2.2; min=1.6; max=3.0)

A closer look at PR and Disability

OVID MEDLINE and CINAHL search on various combinations of generic 'disability' and participatory research produced 30 publications (22 remained after removal of duplicates and criteria eligibility) between Jan 1996-Oct 2006

Number



Service user involvement a new form of tokenism? Ethos and evidence

- Where is the evidence-base for how PR works?
- Which PR processes and strategies work more effectively than others in producing research outcomes?
- What outcomes can be achieved through various PR strategies that meet scientific rigor and participatory involvement criteria?

Barriers to Participatory Research (PR)

- Limited understanding of PR in the research community
- Traditional positivist research orientation dominates and cements attitudes that prevent adoption of a broader scope of evidence-building designs and methodologies
- Status, knowledge and competence differences between the research, practitioner and service user communities
- Insufficient (“non-tokenistic”) consultation of service users in defining research priorities (policy level) and research questions (research level)
- Lack of communication between researchers and service users about the research objectives and intended outcomes

Strategies of enhancing PR

- Mutual agreement among researchers, practitioners, and service users about relevance and definition of research questions, methodologies and outcomes
- Use of setting sensitive mixed-method designs
- Involvement of service users at all stages of the research and evaluation process
- Training of researchers in participatory methods and applications under close involvement of people with disabilities

Towards 'Evidence participatory disability research'

Evidence based participatory disability research is the conscientious, explicit, and judicious use of current best evidence that is co-produced, environment-, situation- and context-sensitive and that integrates individual stakeholder expertise, experience, and systematically derived research findings

The process of identifying best strategies of enhancing participation in research is ongoing, requires a reflective stance on those engaged in research, identification of best practices in moving from participation to active involvement of people with disabilities at all stages of the evidence generation and translation process.

Thank you!

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