

Priority setting using the Dialogue Model

Janneke Elberse

Athena Institute, VU University Amsterdam

j.e.elberse@vu.nl

International Workshop
Research Agenda and Priority Setting
1st – 2nd June 2011
University of Plymouth, Plymouth



The Dialogue Model for priority setting in health research

- **Why** a multi-stakeholders dialogue to set priorities?
- **How** to shape such a priority setting process?
- **An example:** research agenda Burns
- **Challenges**

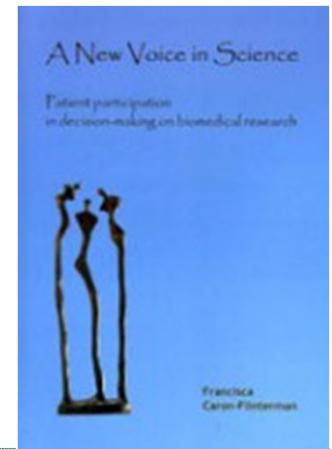
Why a multi-stakeholder dialogue?

Different stakeholder groups can have complementary perspectives

Funding agencies want more legitimacy and fund research addressing needs of target group

Patients/citizen want more influence and involvement

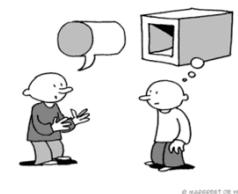
“Need for dialogue and collaboration”



Why a multi-stakeholder dialogue?

Win-win situation for both science and society

- Gains for research:
 - > Research address needs from different stakeholders
 - > More enriched, contextualized research
 - > More support for research
- Gains for society:
 - > Research more corresponding to needs from different stakeholders
 - > Contribution to health research, increased understanding
 - > Increased empowerment



© MAGDALENE DE HOF

How to shape such a priority setting process?

- Dialogue model is developed over period of 15 years:
 - Developed ‘prototype’ based on literature
 - Tested this through social experiments
 - Reflected on and adapted the model
- Combines the ILA-approach and ‘responsive evaluation’
- Focus initially on research agenda setting and policy development



Dialogue Model: The principles

- Active engagement of relevant stakeholders
 - On equal footing (attention for power-relations)
 - With influence on decision making
 - Specific attention for diversity
- Good social conditions
- Respect for experiential or practical knowledge
 - Input visible and recognizable for participants

Dialogue Model: The principles

- Dialogue between stakeholders
 - Knowledge co-creation between science and society through *mutual learning*
 - Actors listen respectfully to each other
 - Are willing to revise their point of view
 - Substantive and reflexive
- Emergent and flexible design
- Neutral and structuring process facilitation

Dialogue Model: The phases

The Dialogue Model

1. Preparation and exploration
2. Consultation
 - a. assessing problem framings
 - b. identifying research priorities of different stakeholders separately
3. Prioritization per stakeholder group
4. Integration of different perspectives
5. Programming and action planning
6. Implementation of program

Consultation &
opinion
development



Dialogue

Dialogue Model: Cases

Developed research agenda's:

1. Dwarslaesie (2003)*
2. Asthma/COPD (2004-2005)
3. Renal failure (2005-2007)*
4. Intellectual disabilities (2006)+
5. Burns (2006-2007)
6. Diabetes (2006)
7. Neuromuscular diseases (2006-2007)*
8. Congenital Heart Conditions (2007)
9. Cystic Fibrosis (2007)^
10. Respiratory diseases (2009)
11. Medical product development (2010)
12. Alzheimer's disease and Dementia (2011)
13. Lyme disease (currently executed)
14. Bipolar disease (currently executed)
15. Visual impairments (in preparation)

* Executed by CAPHRI

+Executed in collaboration with CAPHRI

^Executed by organisation itself

Dialogue Model: An example

The case of the Dutch
Burns Foundation

Bhurns project

Dialogue Model: An example

1. Preparation and exploration
 - Identifying relevant stakeholder groups
 - Exploring social conditions
 - Choices made for methodologies
 - Literature and deskstudy
2. Consultation (identifying research topics per stakeholder group)
 - scientists, burn survivors, parents of young burn survivors, health professionals
 - focus groups, interviews
3. Prioritization
 - Questionnaire, delphi rounds
4. Integration by means of a Dialogue Meeting
5. Programming and implementation is done by Dutch Burns Foundation

Dialogue Model: An example

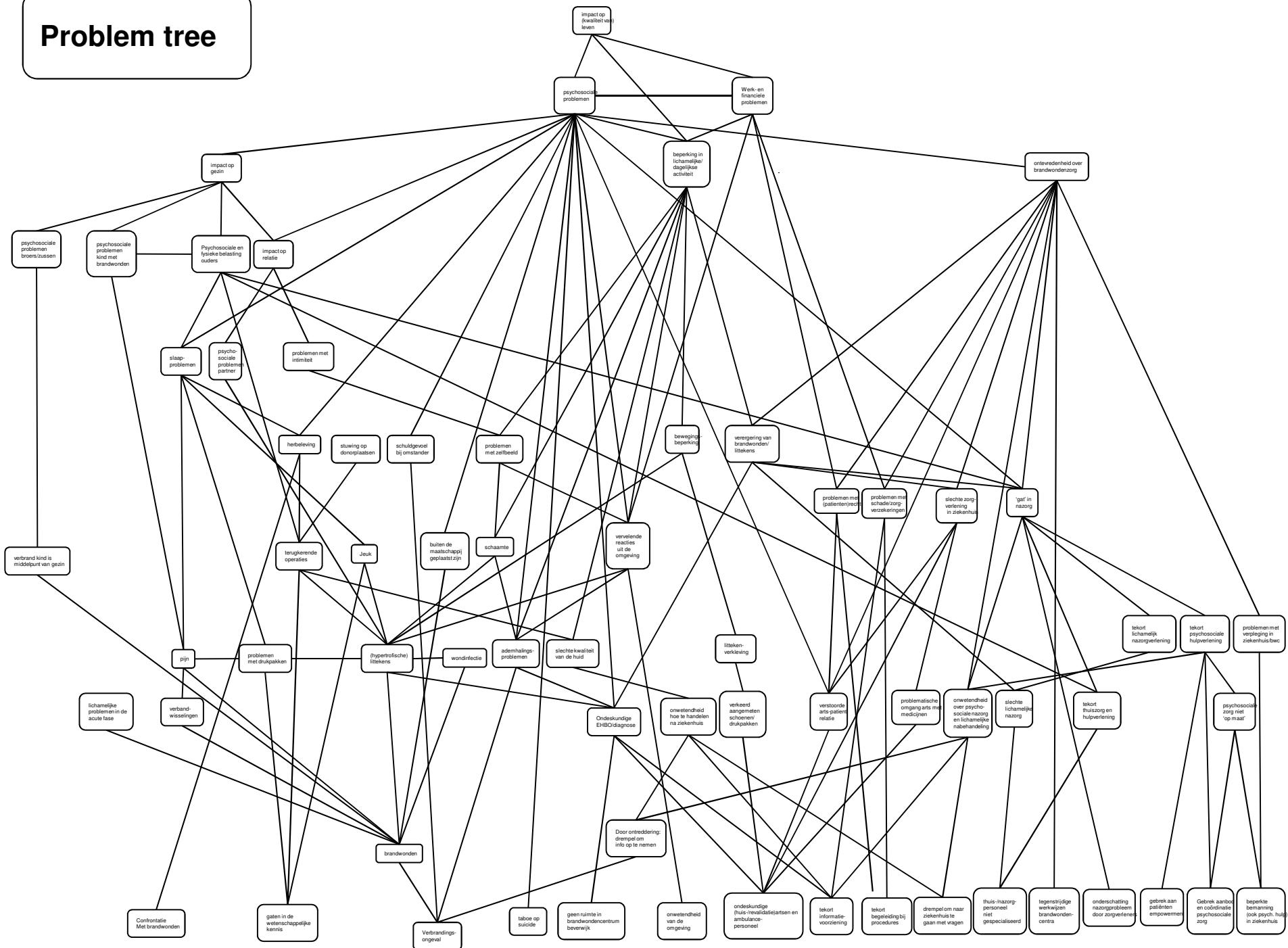
Identifying priorities of burn survivors

- Literature & interviews
- Focus groups (5 groups, 37 participants)
- Questionnaire (n=224)
- Feedback meeting

15 topics (input P4)



Problem tree



Questionnaire

Part I: general characteristics

Part II: prioritize research topics and themes

Part III: evaluative questions

- 10 themes → top 4
- Each theme comprises 6 topics (60 total)
 - per theme top 3

	D
	F
	C

Based on literature,
focus groups and
feedback meetings

Dialogue Model: An example

Identifying priorities of professionals

- || Policy plan VSBN (2004-2008)& interviews



- || Interviews &

3 meetings

(20 participants)



Psycho-social and rehabilitation

Basic research

Prevention



- || Delphi round

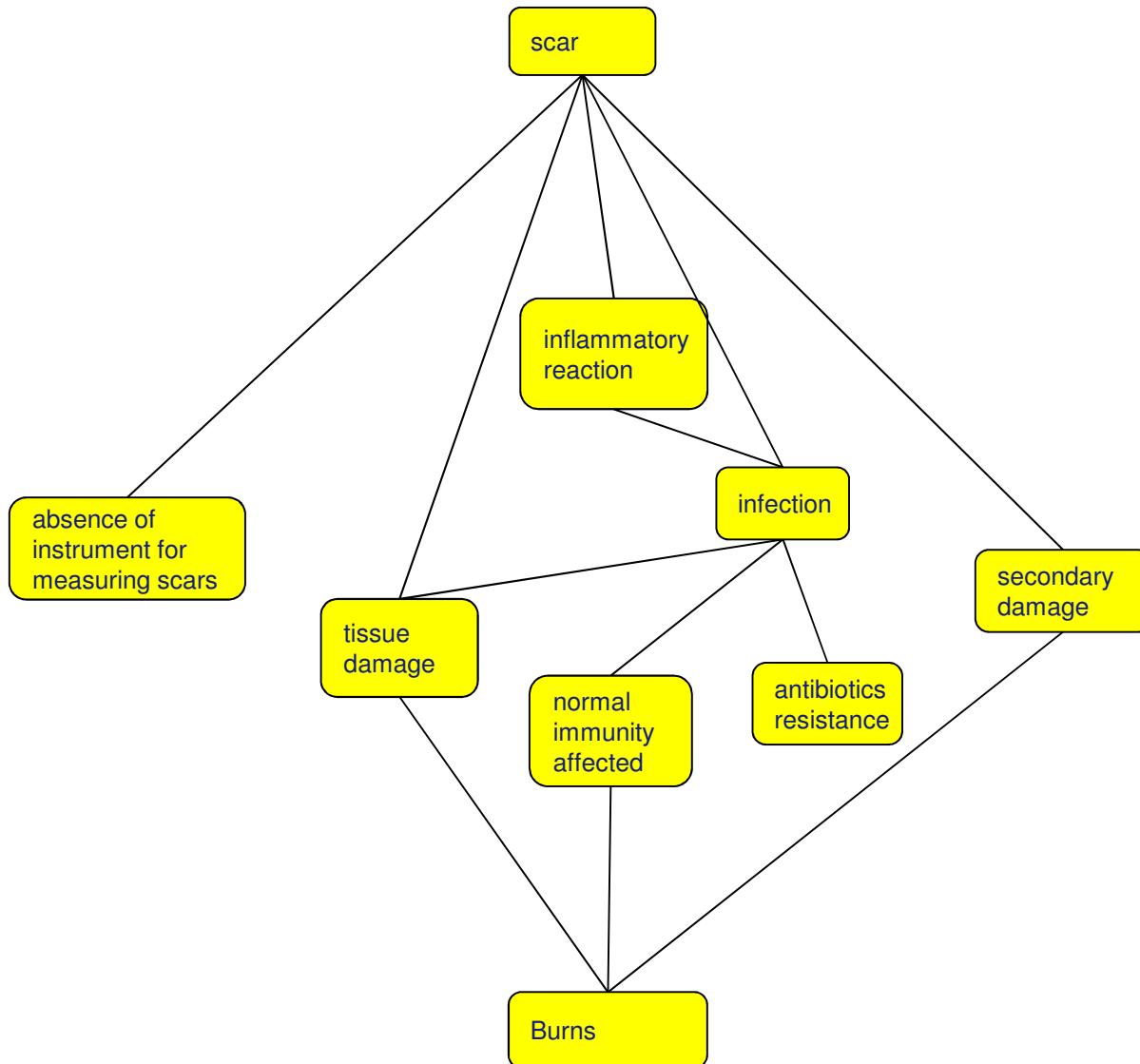


10 topics

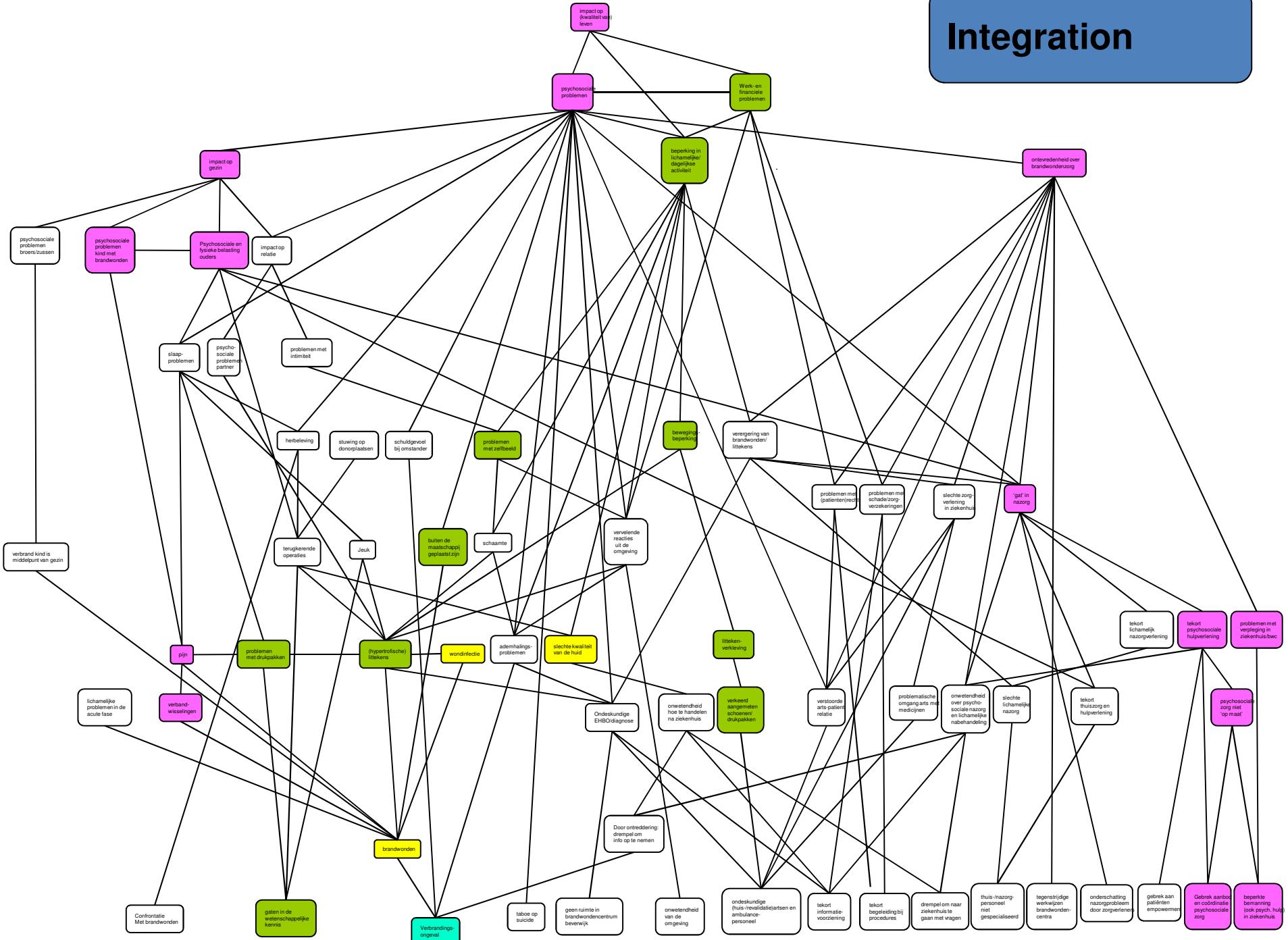
11 topics → (input P4)

5 topics

Basic research



Integration



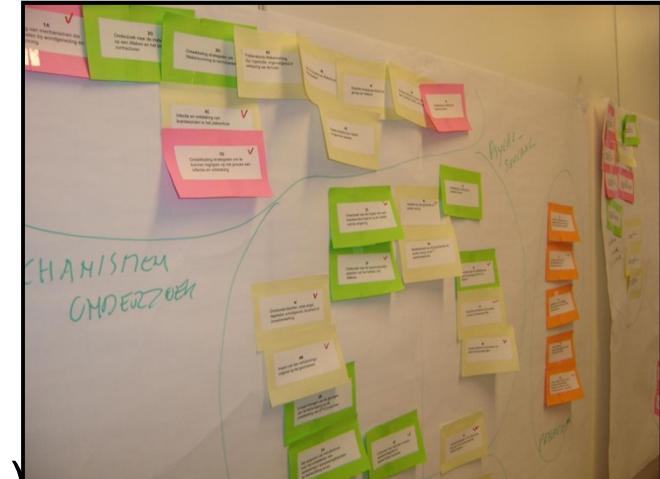
Dialogue Model: An example

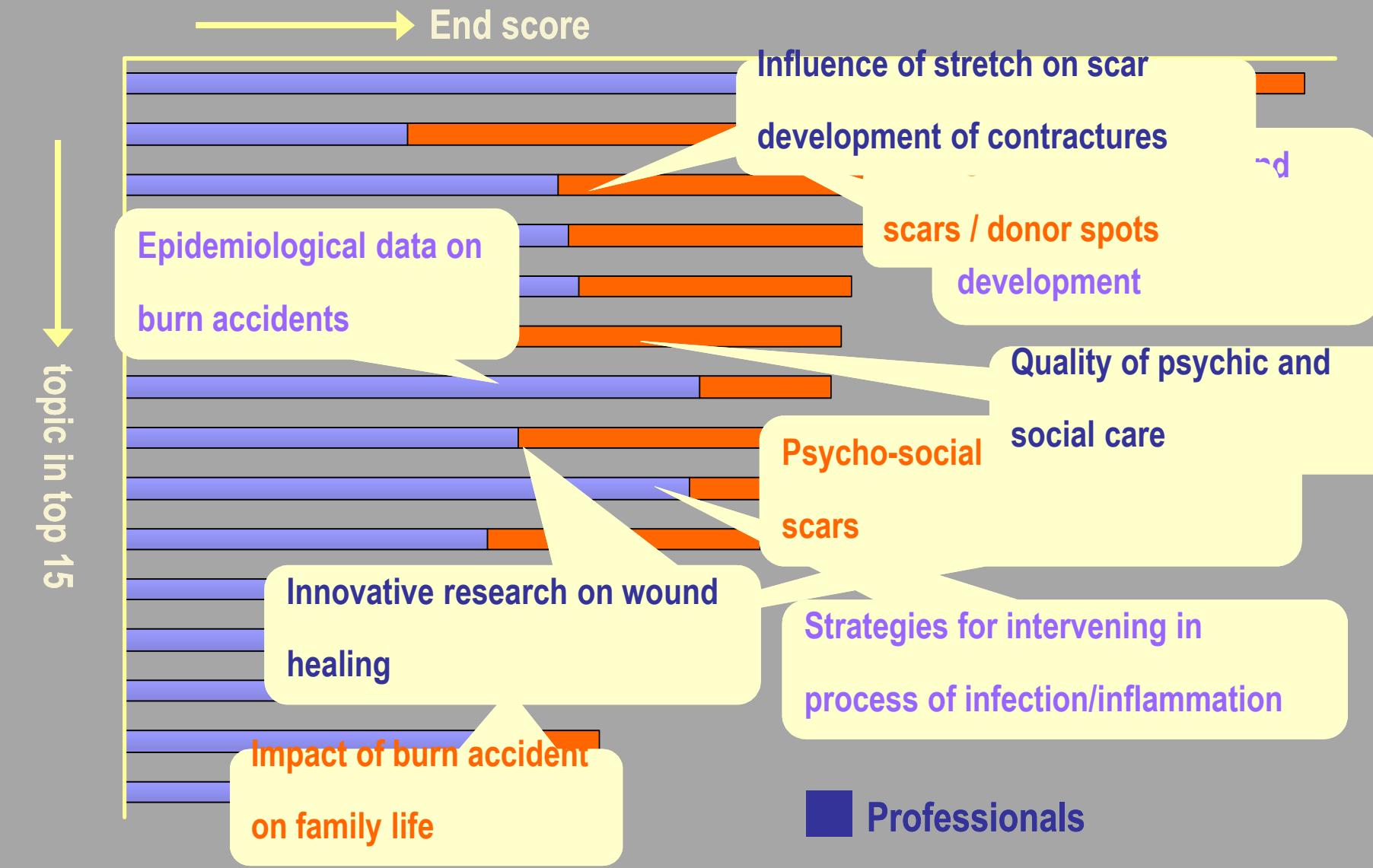
- Topics mentioned by burn survivors are broad
→ lack of attention for prevention
- Topics of professionals give more detailed ‘picture’ of part of topics mentioned by burn survivors
- Good starting point for dialogue meeting

Dialogue Model: An example

Dialogue meeting

- 30 participants: 15 people with burns and 15 professionals
- Discussion of 4 priority lists (differences, similarities, ‘blind spots’)
- Integration into one list with 7 themes and 41 research topics
- Prioritization of integrated list
7 themes placed in order
selection of **top 15** of research topics





Dialogue Model: An example

Phase 5 and 6 executed by the Dutch Burns Foundation itself

- Priorities taken up one-on-one in research agenda
- No stakeholders involved in these phases other than scientific advisory board
- Evaluation after 2 years: no proposals for research on itching; funding allocated and actively approaching suitable research groups
- Currently considering an update and extension to include citizen, children, research nurses etc.

Dialogue Model: An example

- Impact on research agenda DBF:
 - Part of the agenda overlapped with current priorities
 - New topics:
 - Itching on scars and donor places
 - Psycho-social aspects and care
 - Prevention – epidemiological data
- Impact on patient organization
 - Increased interest in research
 - More contact with Burns Foundation
 - Feelings of empowerment
 - Start of a buddy system

Dialogue Model: An example

- Dialogue Model was useful to set research priorities with multiple stakeholders
- Broadly supported research agenda for burns
- Patients were able to set research priorities
 - Attention for long-term and short-term research
 - Input of new research topic (itching and oedema)
- Each stakeholder group had ‘own’ priorities, but groups also prioritized each others topics → mutual learning
- Clear impact on charity fund and patient organization

Challenges of the Dialogue Model

- Current ways of thinking and acting among stakeholders
 - Science: reductionism, autonomy, publish or perish and lack of competences in transdisciplinary research
 - Hierarchical relations: danger of tokenism
- Adherence to scientific quality criteria (scientific quality, validity, reproducibility) versus quick results or societal relevance
- It takes time and costs money (funding)
- Sustaining science-society interactions beyond project
- Lack of knowledge exchange – reinventing the wheel
- Set priorities is no guarantee that research is done on these topics
- When to update the agenda and who to include?

Some relevant publications

- Patient participation as dialogue: setting research agendas.
Abma et al. (2010) *Health Expectations*
- A new voice in science. (2005) Caron-Flinterman, *PhD-thesis*
- Involving burn survivors in agenda setting on burns research: an added value?, Broerse et al. (2010) *Burns*
- Patient–expert partnerships in research how to stimulate inclusion of patient perspectives||Broerse et al|| (||) ||ealth ||xpectations
- Enhancing a transition towards a needs-oriented health research system through patient participation||Broerse et al|| (||) in ||||| Broerse and ||unders (||ds||), ||transitions in ||ealth ||ystems ||ealing with ||ersistent ||roblems |||| University ||ress, ||sterdam||

A photograph of several students sitting at wooden desks in a lecture hall, looking down at their papers and writing with pens. The focus is on two students in the foreground: one with blonde hair on the left and one with dark hair and glasses on the right. The background is blurred.

THANK YOU

QUESTIONS?