

Eurocarers research priorities – an update

Henk Nies

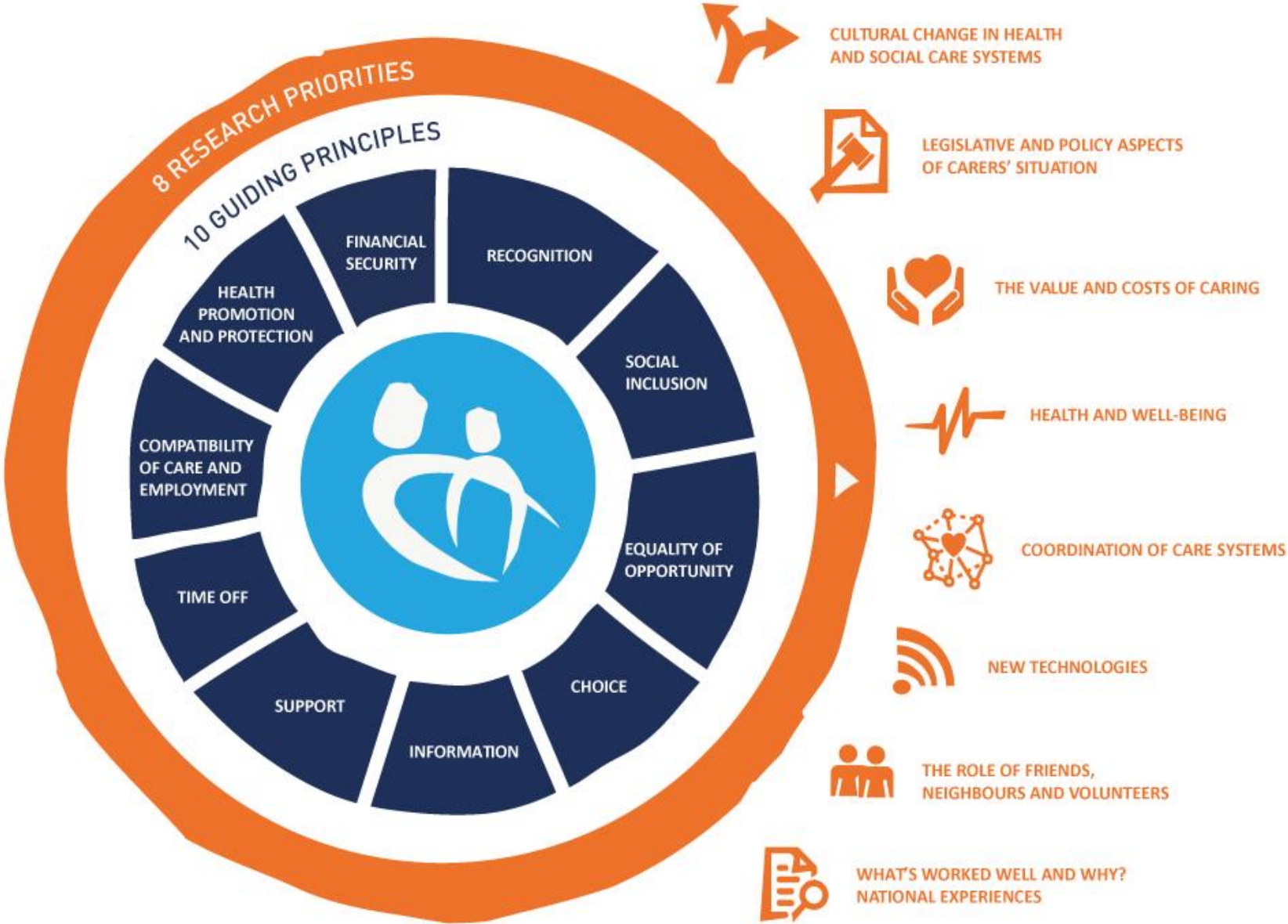
Vice-president Eurocarers

Vrije University Amsterdam

1 December 2023



Eurocarers: guiding principles and research



Our priorities in 2015

- Cultural change in health and social care systems
- Legislative and policy aspects of carers' situation
- The value and costs of caring
- Health and well-being
- Coordination of care systems (at all levels)
- New technologies
- The role of friends, neighbours and volunteers
- What's worked well and why? Documenting and exchanging national experiences

Our thinking (GL & HN)

- Conditions for care provision of IC (after Covid)
- Long term effects of Covid among ICs and care situations
- Implicit costs of IC (under 'costs')
- Impact on socio economic conditions
- Impact of increased mobility and urbanisation
- Labour market participation (incl. gender differences); balancing care and work
- Skills and competencies of informal carers
- Professional carers who are IC as well
- Deployment of (non-)paid laymen, citizens, volunteers, migrant workers; integrating ICs in formal care systems; caring neighbourhoods
- Administrative burden on ICs
- Tailoring policy and practice to diversity of needs of ICs
- Ethics of informal care irt formal care
- Scaling up implementation

Methodologies

- Aims of research: to contribute to learning, improvement and implementation of appropriate care and support
- Effectiveness of interventions and measures
- Research based on Theories of Change/Logic Models
- To contextualise research
- Involvement of and co-design with ICs in (participative) action research endeavours and policy development
- RCT's are not the 'gold standard' for research into LTC
- Include: participatory action research, responsive evaluations, appreciative inquiry, qualitative and multiple method designs approaches, narrative and ethnographic research, realist evaluation
- Critical on large scale data collection: validity, reliability, generalisation, expenses, explanatory value, administrative burden

Questions

- Which themes are most relevant for the near future (your 'top three')?
- Are there any themes that are sufficiently addressed by research?
- Which themes or additions to the current should be added?

How to ensure an effective translation and implementation of research outcomes?

Giovanni Lamura

INRCA – National Institute of Health and Science on Ageing

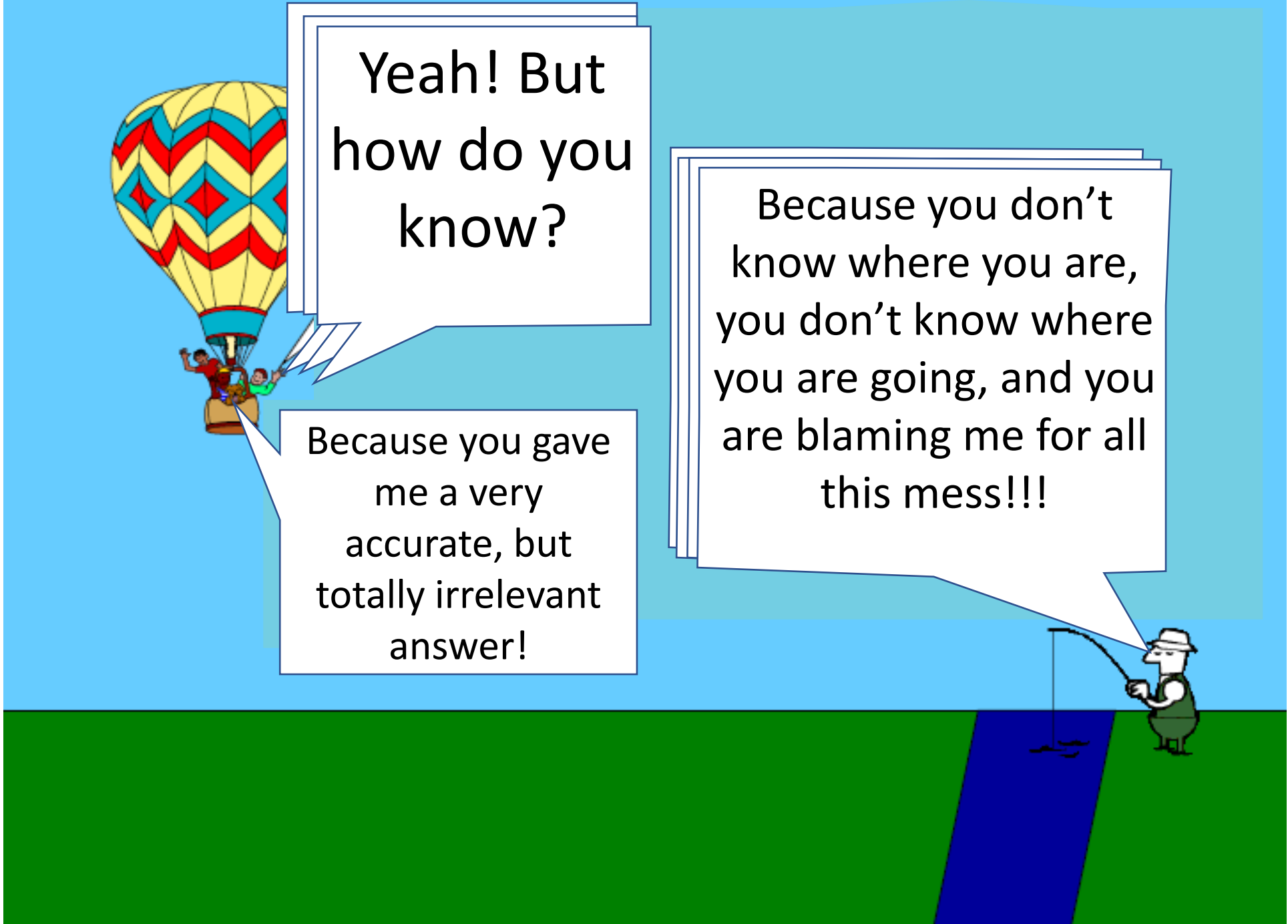
Ancona, Italy

1 December 2023



Exchange of examples & analysis of methodologies/contexts of impactful research

- What was the impact you are positive about, and how was it established?
- What was the context of the implementation?
- What contributed most to this impact?



Yeah! But
how do you
know?

Because you gave
me a very
accurate, but
totally irrelevant
answer!

Because you don't
know where you are,
you don't know where
you are going, and you
are blaming me for all
this mess!!!

Just some initial reflections... (1/2)

1. An effective implementation/translation of scientific findings into advocacy and policy action is desirable and possible, at all levels
2. **Ingredients** (= success factors): availability of:
 - a. expertise able to translate (international / scientific) recommendations into practical/policy action (**top-down?**)
 - b. pragmatic ability to involve civil society organisations in a participatory approach (**bottom-up?**)
 - c. **political will & humbleness** to learn from others, and to collaborate betw. different actors and levels;
 - d. an adequate amount of **funding**.

Just some initial reflections.. (2/2)

3. Major risks & key steps to tackle them:

- a. **lack of visibility:** need to count on sufficient and efficient resources for an ongoing communication campaign to raise awareness in society & policy-makers;
- b. **lack of support / „envy“ by key partners:** need to be inclusive and involve them, thus making clear that success can only be achieved as the result of a joint, common effort;
- c. **resignation or insufficient trust:** need to be clear about urgency of taking action to fight for the rights of informal carers, via adequate initiatives and... be persistent and patient!

Exchange of examples & analysis of methodologies/contexts of impactful research

- What was the impact you are positive about, and how was it established?
- What was the context of the implementation?
- What contributed most to this impact?