

The European Knowledge Tree Group (EKTG)

A short report of outcomes from EKTG Big
Data Session at the September AAL Forum in
Denmark

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Our mission

In co-creation with the field of long-term care, we develop, disseminate and implement innovative and applied knowledge.

To ensure efficient, cost-effective and high quality long-term care and to enhance the quality of life of people who need care and support.



- Independent
- Co-creation
- Knowledge
- Hybrid financing
- Not for profit



Professions / Teams

- Advise & Implementation (advisors)
- Research & Innovation (researchers)
- Marketing & Communication (dissemination)

Teams/Themes, e.g., Personalized Healthcare, Integrated Care, Community Care, Quality, Online Learning, eHealth...



Innovatie & Onderzoek

+



Kennis Ontwikkelen & Delen

+



Advies & Implementatie



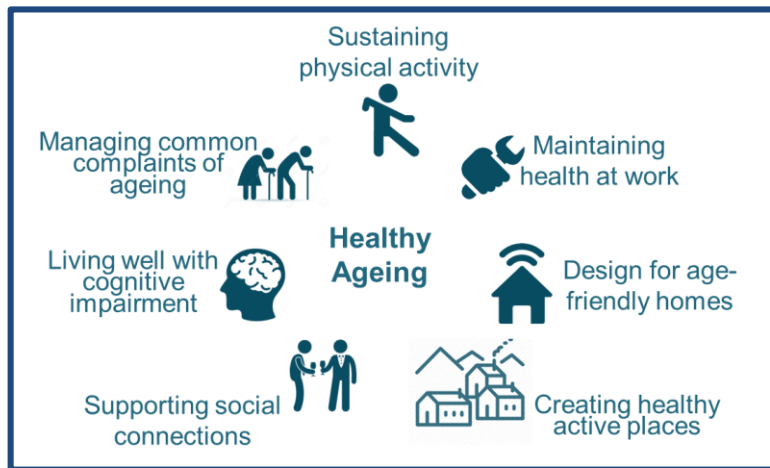
Benefits & Challenges of Data

- Example benefits:
 - Reducing readmissions
 - More efficiency & effectiveness
 - Better quality of life
 - Better health products and services
 - Challenges
 - data quality
 - diversity
 - data protection
 - interoperability
- and
- tendency to lock up rather than share data
 - uncertainty to give access to data
 - rapid rise of user generated real world data
 - pervasive interest in Europe-wide solutions but lack of plan and leadership



Healthy Ageing Challenge

Huge opportunities for smart services



* The Challenge themes, developed by the Centre for Ageing Better, offer the greatest opportunities to tackle market failures and stimulate innovation

If the ambition is to impact on the lives of millions of people within a decade:

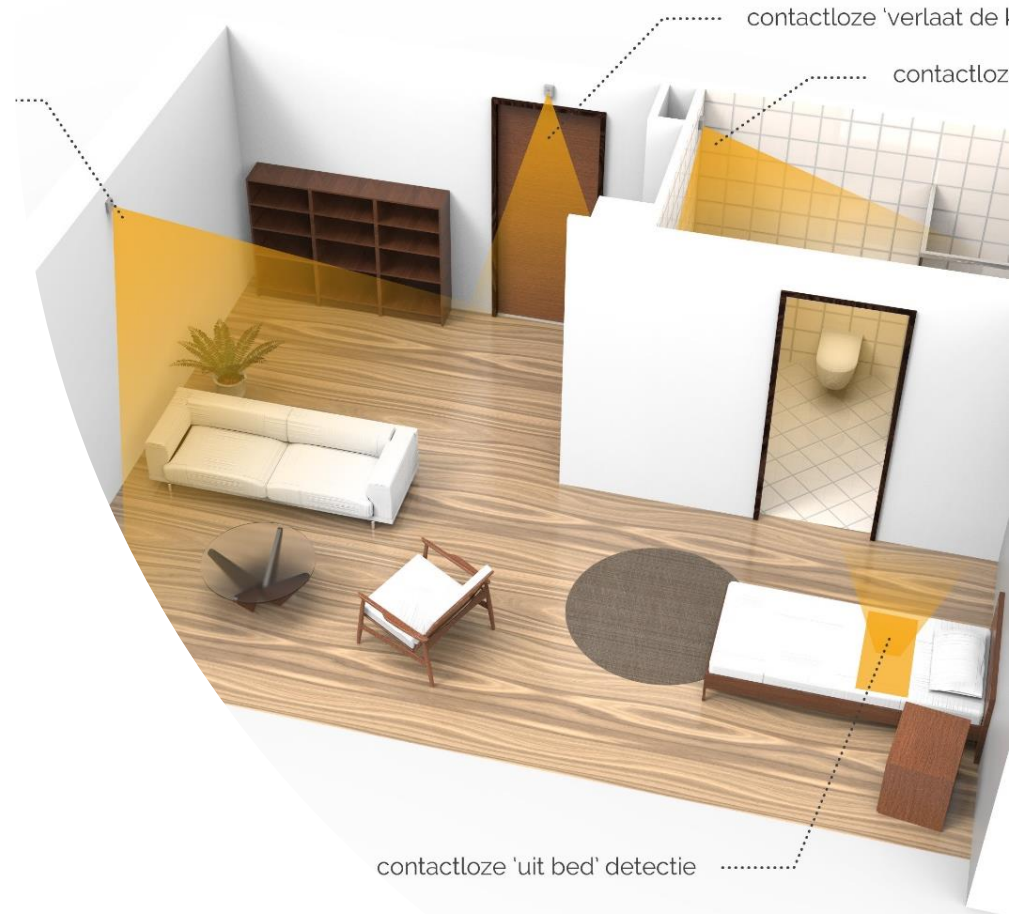
- Recognise market failures
- Focus on enabling smart *services*
- Disruptive business models are needed

While being responsible:

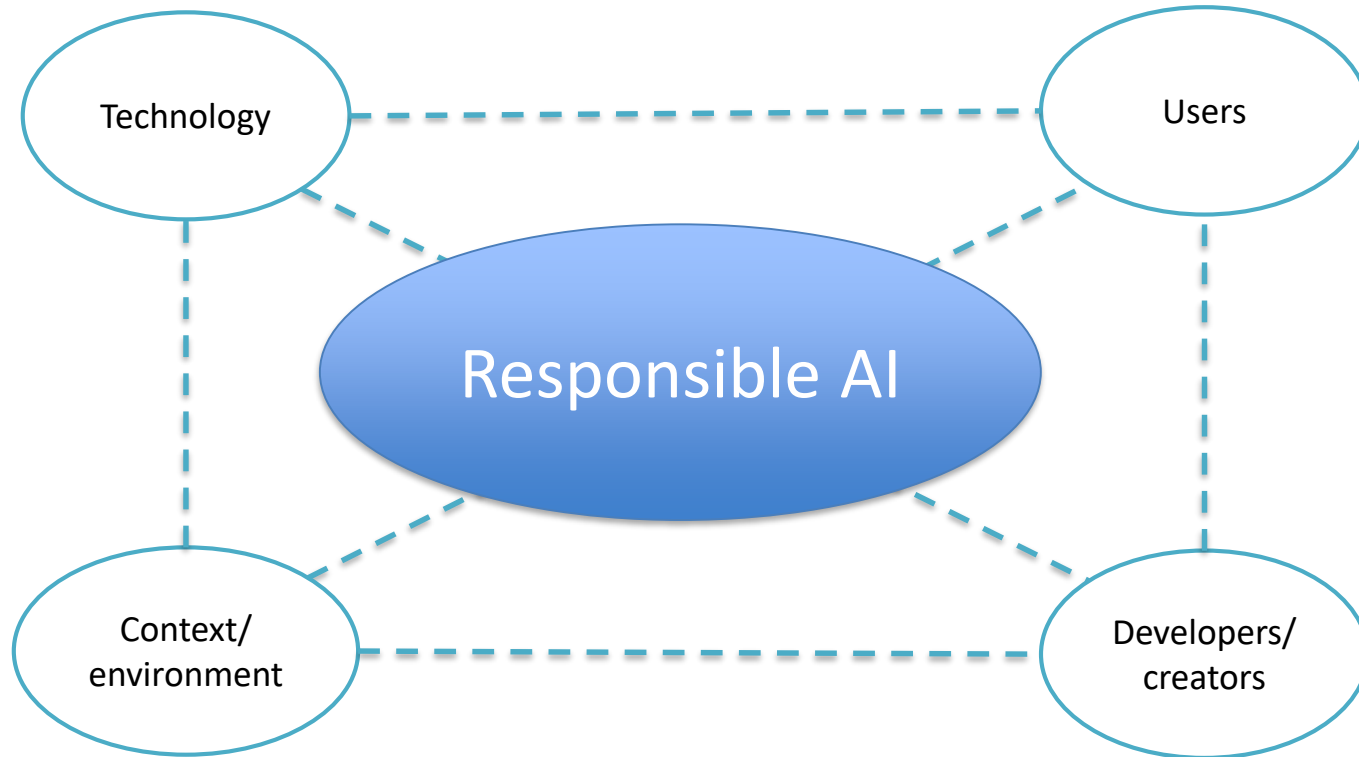
- Recognise that citizens fear technology is an excuse for withdrawing human contact
- Establish a 'deal' to get value from sharing data
- Learn from successful outcomes-based contracting models such as the Argenti partnership in Hampshire

Co-creation of data

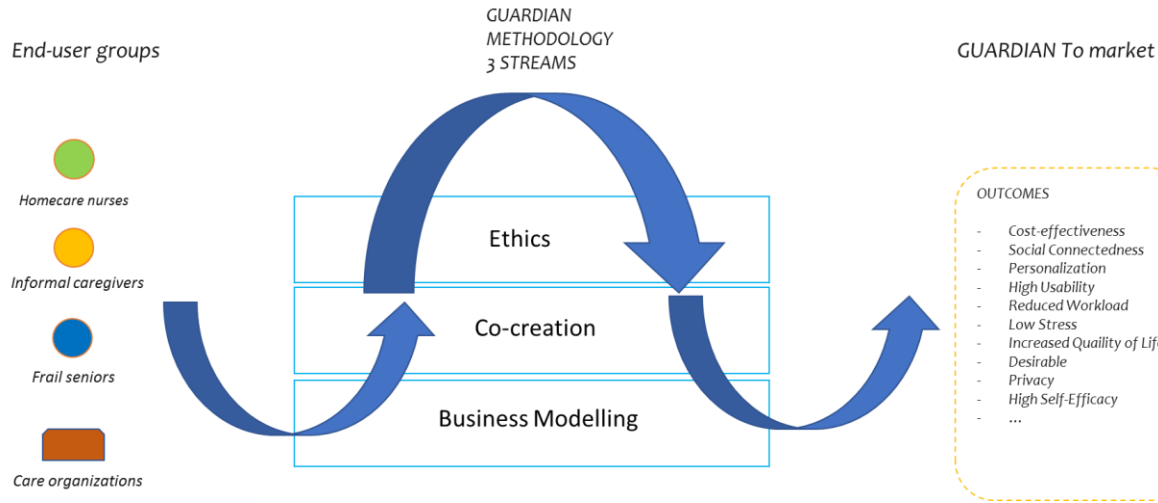
- Objective & subjective data
- Confirmation by end-users on data (objective data is valuable, but what does the client say or feel?)
- Annotation of data (e.g. is stress really stress?)



Responsible AI requires actions around technology (design), environment (implementation) and use(r)s (who require new skills or attitudes). But what is the place of users and (their) context in this process?



Ethical considerations from early design to local use



Fast & Responsible

- Fast?
 - The need to deliver user benefits sooner rather than later
 - The need for Europe to be international competitive in health & pharma
 - No KPIs yet
- Responsible? ...
 - Considering user rights and respect
 - E.g. support in data space for data protection
 - E.g. piloting the Guidelines on AI & Ethics of the EC's High-Level Group
 - KPIs may develop, also in view of legislation (GDPR, coming AI law)



Management of health and care data access and control is crucial

Fundamental principle:

Health data belongs to the data subject

- ✓ Access to my data
- ✓ Control of my data
- ✓ Delegation of my access and control rights

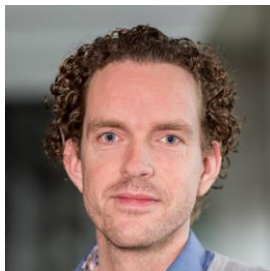
Legal framework functions in combination with appropriate **technology** and **governance**



Thank you!



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