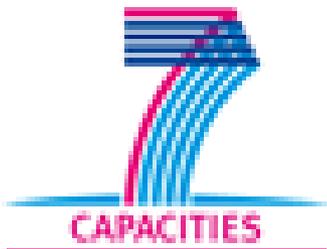


EFORTT: ethical frameworks for
telecare technologies for older people
at home
European Commission FP7 (Science in Society)

Final report, ethical framework & booklet for users
& carers can be downloaded from:

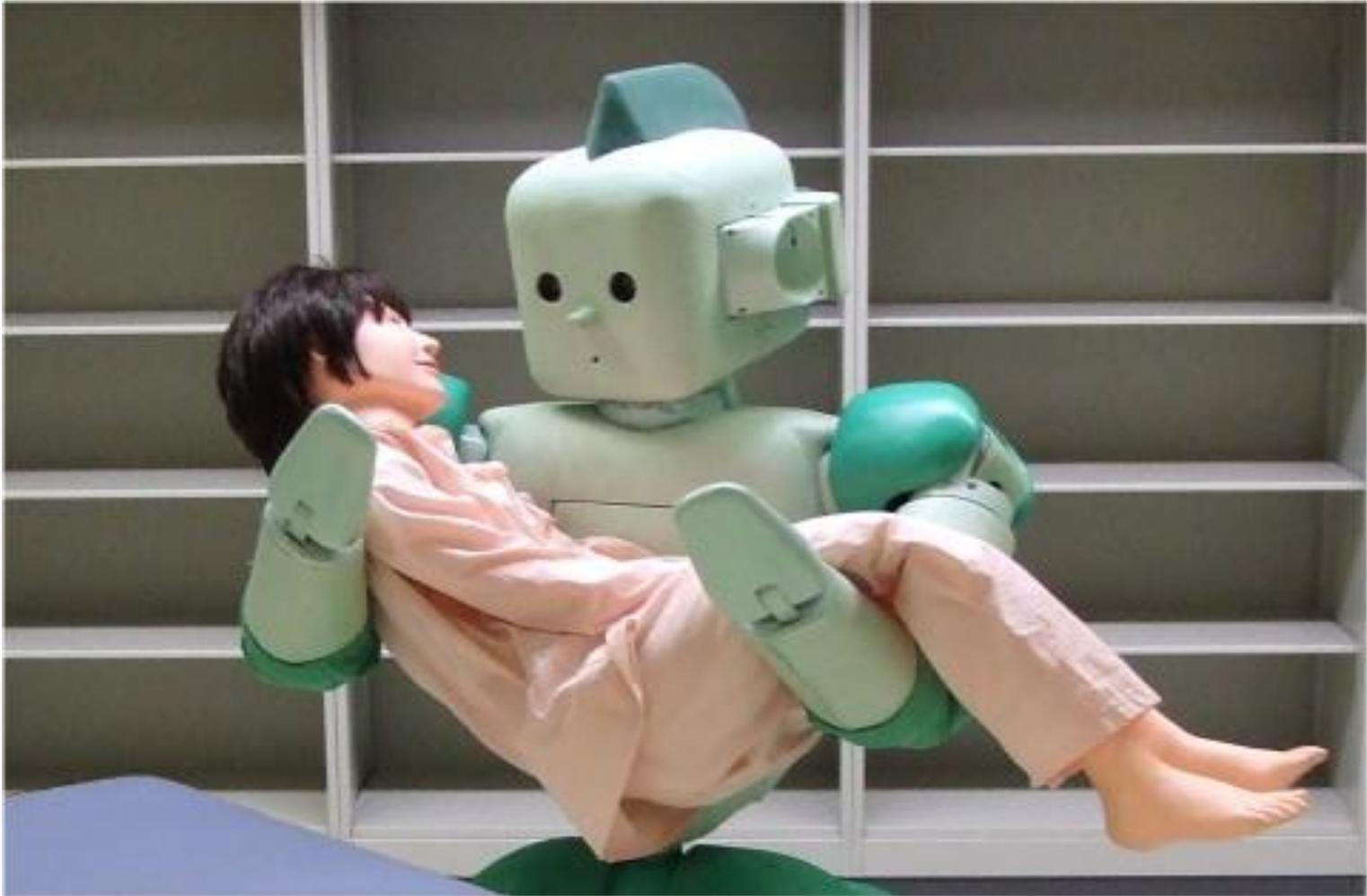


www.lancs.ac.uk/efortt/

Different generations of telecare



'Ri-Man' care robot



EFORTT projects

Spain: Telecare and Red Cross implementation of new 'dependency' law

England: Telecare and Local Authority policy/implementation

Netherlands: Health Buddy & online 'PAL4'

Norway: Dementia care/smart homes/sensors & carers web space



Approaches to ethics: principles

Autonomy: respecting the decision making capacities of autonomous persons, enabling individuals to make reasoned, informed choices

Beneficence: balancing the benefits of treatments against the risks and costs; the healthcare professional should act in a way that benefits the patient

Non-maleficence: the healthcare prof should not harm the patient, or any harm should not be disproportionate to the benefits of treatment

Justice: distributing benefits, risks and costs fairly, patients in similar positions should be treated in similar manner

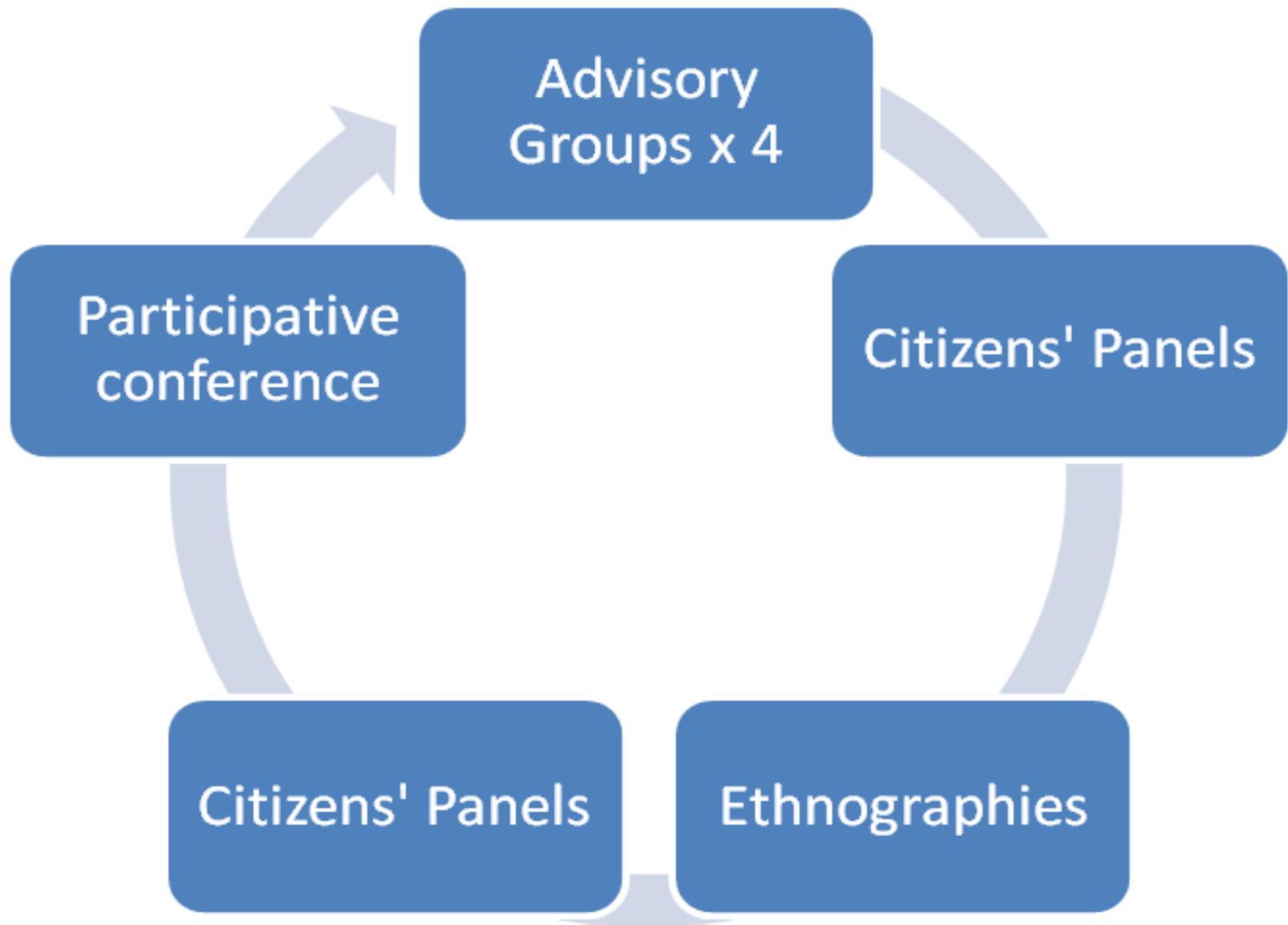
Ethics of telecare *in use*: empirical

We found a wide range of forms of telecare 'usage'

- refusal
- intermittent use
- misunderstanding
- installation to meet targets
- 'misuse'
- adaptation
- creative use
- customization and supplementation

Complexity of the telecare network

- Older people (assessed as at risk)
- Social services: managers and social workers
- Houses (the individual's home)
- Call/monitoring centres
- The Government
- Technology developers
- Care organisations (home care workers)
- Families, neighbours and friends
- Bed sensors, door monitors, smoke alarms...
- Technology providers and installers
- Emergency services



Concerns raised by older people and telecare workers

- Loneliness - *social* use seen as 'misuse', yet reveals need for contact
- Widespread concerns about 'replacement' of face to face care
- Need to integrate telecare with existing strategies
- Active/passive distinction (pendant seen as active; sensors seen as passive)
- Intrusion in the home (esp more complex systems)

'Active' usage of telecare

I have a Lifeline and it gave me the confidence at home to do things [respondent uses wheelchair]. I had the confidence to move around the house.... I would practice standing up and getting things because I knew that if anything had happened I could do that [pendant]. If I hadn't have had that, I'd have thought 'I'm on my own now, I'd better be careful.' When I go to my friend in XXX, I'm sat on her settee and I'm told not to move. You see I don't have a Lifeline or anything there, and I actually feel a bit trapped. That pendant round my neck gave me the confidence to try things on my own, without somebody saying 'Oh you shouldn't do that'..... This is the first time in the 8 years that I've had it, the first time I've actually sat here and said to anybody what it means to me, because nobody asked me.

(Citizen's Panel)

Older people & carers: disruption of home

The white box is at the bottom of the stairs ..connected into the telephone thing. So what would happen is I'd be lying in bed & hear this Pop pop, Peep peep, like a dial-up modem type of thing & I'd wake up & think 'Oh, here we go!'. Then I'd come downstairs & it would go through this 'Beeeeep, Urrr, Beeeeep, Urrr', & go on for ages & ages, very very loud. I'd put my hands over it, with my eyes closed, still in sleep mode, & then after a while it would get through & there'd be a really loud muffled voice on the other end, barely decipherable saying: 'Are you all right? Is there any problem?' And I'd say, 'No, it's a false alarm', & they'd say: 'Okay', then go back to bed. And sometimes it would go again an hour later.

The call monitoring centre

D: *The most difficult calls for me are the telecare and the fire and the CO or gas detectors, **they worry me no end.** I really don't like them when they come through, I do tend to think [gasp] God! We have a procedure, but I think how long will it take to get someone there?*

I never leave a call...

MM: So if a call comes through and you're not sure how the person is - they're confused - how do you deal with that? Because you can't see them, you can't touch them, you can't - how do you manage?

D: *Listen to the conversation and make my mind up what is going on, and then nine times out of ten I would get someone to go and check on them. I would never leave an elderly person.... they say things and you can't really... take for granted they'll be all right ... I **never leave a call, I always get someone...** it's not worth it.*

We're having a bad nightmare

A: *With the bed sensor, it tells you when they get out, and you do try and speak to the people just to make sure they haven't fallen ... There's one lady, she wanders all night long. Just moving herself. She has bad nights, she doesn't sleep very well.*

B: *We sing lullabies to her. I usually say 'It's too early now, get back into bed, night night, God bless' and **they like you to talk to them like that**, [when]... you're lovely with them. You can talk to her.*

A: *You say 'We're having a bad nightmare, let's have a brew!' [chuckles]*

CR: *really?*

A: *Yes, she'll go and... because she's capable, make herself a cup of tea.*

Work in care monitoring centres

- Involves multiple tasks, particularly at night
- Mediation between formal carers, informal carers and emergency services
- Working with indeterminacy & uncertainty
- A field in which workers try to repair associations for older people, to stitch together 'the social' from fragments of connection and information
- Is this just 'technical' work?

This seems to mean that...

- Telecare relies on 'traditional' networks of people and practices of caring (on 'society')
- Telecare cannot actually provide care
- 'Telecare workers' attempt to repair 'the social network' with limited resources, which costs them a lot emotionally

In an ethical telecare service:

- Recognition it meets some needs not others
- 'Misuse' seen as unmet need
- Services are flexible and adaptive to allow for change/deterioration
- Older people are involved in ongoing engagement with service practice and design
- Telecare involves a 'care network' where roles are better understood (e.g. monitoring centre workers better supported)

Practices for ethical telecare.....

- **Consultation:** establish older peoples' telecare groups
- **Address social isolation:** specify pro-active contact; address 'misuse'
- **Consent as a process:** revisit as conditions change
- **Technology:** review sourcing to minimise intrusion; bottom-up feedback to address design problems
- **Intelligence:** patterns of use fed back to prescribers
- **Consider both economic and social costs in evaluation**

Provider features of the framework

- Installation complexities: need for follow up with 'user' re workability
- Recruitment: importance of staff background
- Expansion issues/fear of outsourcing/pressure of numbers
- Local knowledge and care background/experience essential to service
- Training: ongoing education/support/counselling:
(‘I’ve had people die on me, which to this day upsets me, because I couldn’t be with her, and I knew when she came on to me she’d die.....’)

Why adopt the EFORTT ethical framework for telecare?

- Helps to implement service more effectively
- Assists with risk management
- Helps meet SCIE recommendations
- Offers a self auditing tool
- Clarifies benefits of telecare beyond risk management
- Use in training for operators
- Improves on TSA code of practice
- Helps with legitimacy: framework is evidence based

Recognise that telecare can/does build on people's existing strategies:

arrange things to give peace of
mind.

Tel. in every room.

Key holders.

my friend + I ring each other every
morning.

neighbours know I am around
when my curtains are opened

**Ageing is not
'the problem' :
telecare is not
'the solution'**

Download our
booklet for older
people and
families

And the Ethical
Framework...

E.FOR.TT

**Telecare for older people
living at home**

Questions for potential users and their families

Are you considering having telecare installed at home for yourself or a family member? This leaflet may help you to understand what telecare is and to clarify whether it will meet your needs.

