

Tracking Vulnerable People

Electronic Monitoring & Living with Dementia

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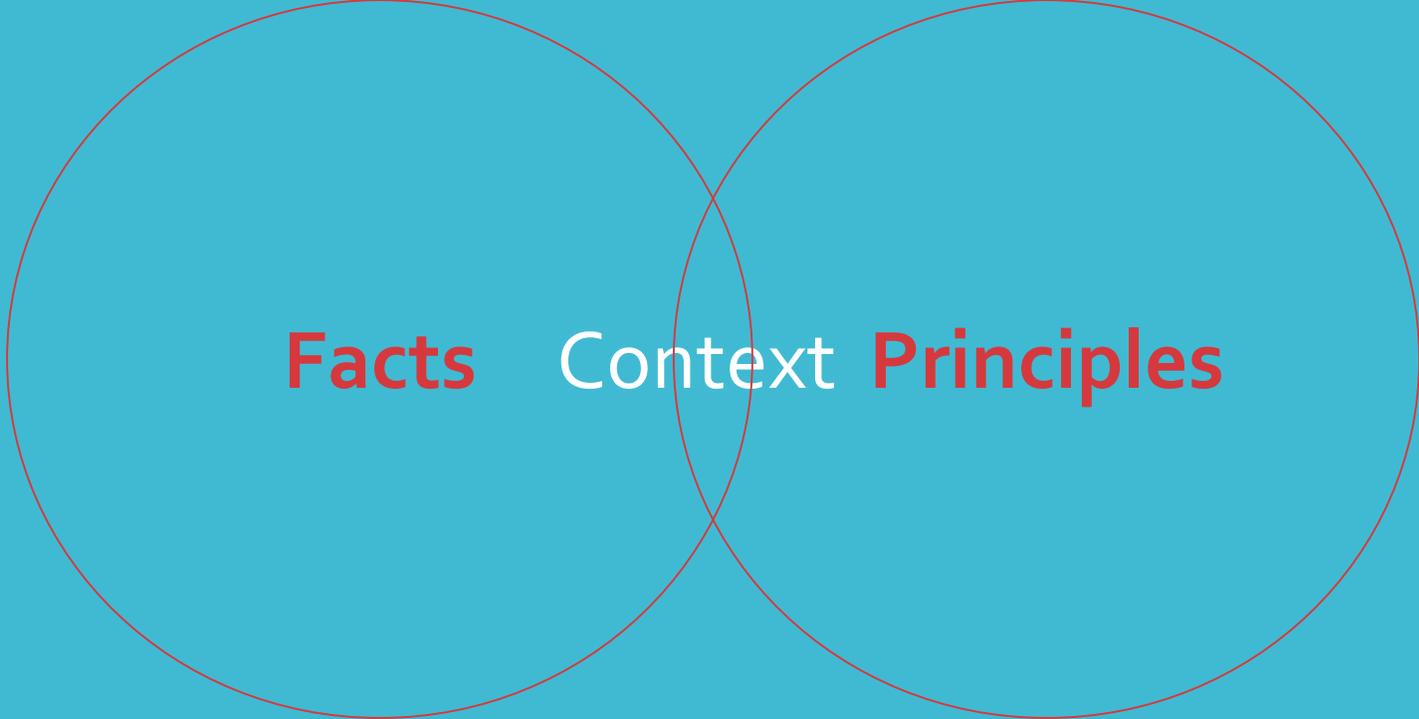
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Tracking People living with Dementia



Facts Context **Principles**

Context

Ageing &
Society

Societal Challenges

Ageing Demographic

Detraditionalisation

Receding Welfare State

Technological turn

Ageism

Constructions of Ageing

Constructions of Dementia

Electronic Monitoring in Later Life

Smart Homes

Sensors e.g. falls, blood pressure

Adapted tablets

Robots



Why is Electronic Monitoring so Troubling in Dementia Care?

Facts

Risk prediction in uncertain terrain

Defining harm

How common? What harm? For whom? What cost?

The lens of dementia

Principles

Welfare

Liberty

Privacy

Autonomy

Responsibility

Dignity

The rights of third parties

A study of carers using GPS with Person living with Dementia

How do the ethical concerns play out when people living with dementia use EM?

A study of familial carers' experiences

Bantry White, E. & Montgomery, P. (2014).

Interpreting and applying principles

Motivations

Primacy of physical safety over subjective concerns

Secondary concerns

- Autonomy
- Privacy
- Self-identity
- Independence
- Freedom
- Social connectivity

Making decisions about use

Socio-relational context

- Personalities & risk tolerance
- Relationships
- Carers' needs

Who?

- Capacity and informed consent problematic
- Continuum from covert use, persuasion, consultation to partnership

Interpreting facts

If protection from harm was a key motivator, what is actually known about harm?



Very limited research reliant on media reports & incomplete search records



Study of police missing person reports in the UK

What search & rescue records suggest

How many?

- 0.5% of the regional dementia population

Harm			
Unharmed	266		(94.7)
Sustained harm	13		(4.6)
Found dead	2		(0.7)
Mean age (years) people unharmed	77.9 (<i>M</i>)		(8.30) (<i>SD</i>)
Mean age (years) people harmed	84.1 (<i>M</i>)		(6.64) (<i>SD</i>)
Time (hours) missing people unharmed	1.07 (<i>Mdn</i>)	(0.53 to 2.48) (<i>IQR</i>)	
Time (hours) missing people harmed	3.55 (<i>Mdn</i>)	(0.97 to 9.45) (<i>IQR</i>)	
<i>Mdn</i> Median			
<i>M</i> Mean			
<i>IQR</i> Interquartile Range			
<i>SD</i> Standard Deviation			*unless otherwise stated

(Bantry White & Montgomery, 2015)

Disconnect
between study
on harm and
carer
perception of
harm

Possible Explanations

- Methodological weaknesses
- Freedom so curtailed that limited opportunity to be harmed
- Walking alone outdoors is not terribly dangerous most of the time
- Social construction of risk arises from constructions of ageing, dementia, carers' responsibilities

Aspects that need greater consideration

Making decisions without reliable predictors

- One response could be to focus on assessment of need (Bantry White & Montgomery, 2015a) but problematic

Aspects that
need greater
consideration

Awareness of risks posed by technology

- Risk compensation
- Reliability
- Over-proximity
- Social isolation
- Data protection

Aspects that
need greater
consideration

Socio-relational context of decision-making

- Family systems with histories
- Ethical issues in care work
- Partnership approaches

Aspects that need greater consideration

Implementation

- People living with dementia? Whose voice?
- What purpose?
- For whom is it a problem?
- What alternatives?
- Significance of wider social processes and socio-political context

Some References

- Bantry White, E., & Montgomery, P. (2015). Dementia, walking outdoors and getting lost: incidence, risk factors and consequences from dementia-related police missing-person reports. *Aging & Mental Health, 19*(3), 224-230.
- Bantry White, E., & Montgomery, P. (2015). Supporting people with dementia to walkabout safely outdoors: development of a structured model of assessment. *Health & Social Care in the Community*.
- Bantry White, E., & Montgomery, P. (2014). A Review of "Wandering" Instruments for People With Dementia Who Get Lost. *Research on Social Work Practice, 24*(4), 400-413.
- Bantry White, E., Montgomery, P., & McShane, R. (2010). Electronic tracking for people with dementia who get lost outside the home: A study of the experience of familial carers. *The British Journal of Occupational Therapy, 73*(4), 152-159.
- White, E. B., & Montgomery, P. (2014). Electronic tracking for people with dementia: An exploratory study of the ethical issues experienced by carers in making decisions about usage. *Dementia, 13*(2), 216-232. doi:doi:10.1177/1471301212460445