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# Personal Health and Lifestyle Information in Telehealth Services

Dr Malcolm J Fisk, Senior Research Fellow

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Health Design & Technology Institute, Coventry University

Email: [mfisk@cad.coventry.ac.uk](mailto:mfisk@cad.coventry.ac.uk)



# TeleSCoPE Project (1)



- €960,000 project 60% funded by the European Commission
- Developing a European Code of Practice for Telehealth Services
- Thirteen partners in seven states from Bulgaria to Ireland
  - led by Health Design and Technology Institute at Coventry University
  - others ... academic, user, supply sector and user facing bodies including the TSA

# TeleSCoPE Project (2)



- Consulting on Foundation Papers
  - FP1: Glossary of Terms
  - FP2: Ethics and Good Practice
  - FP3: Overview of the Literature
- See website [www.telehealthcode.eu](http://www.telehealthcode.eu)
- Responses by Mid January (please!)
- Current work includes setting out draft code framework ...
  - Personal data are a major challenge!

# TeleSCoPE: Definitions

## Telecare

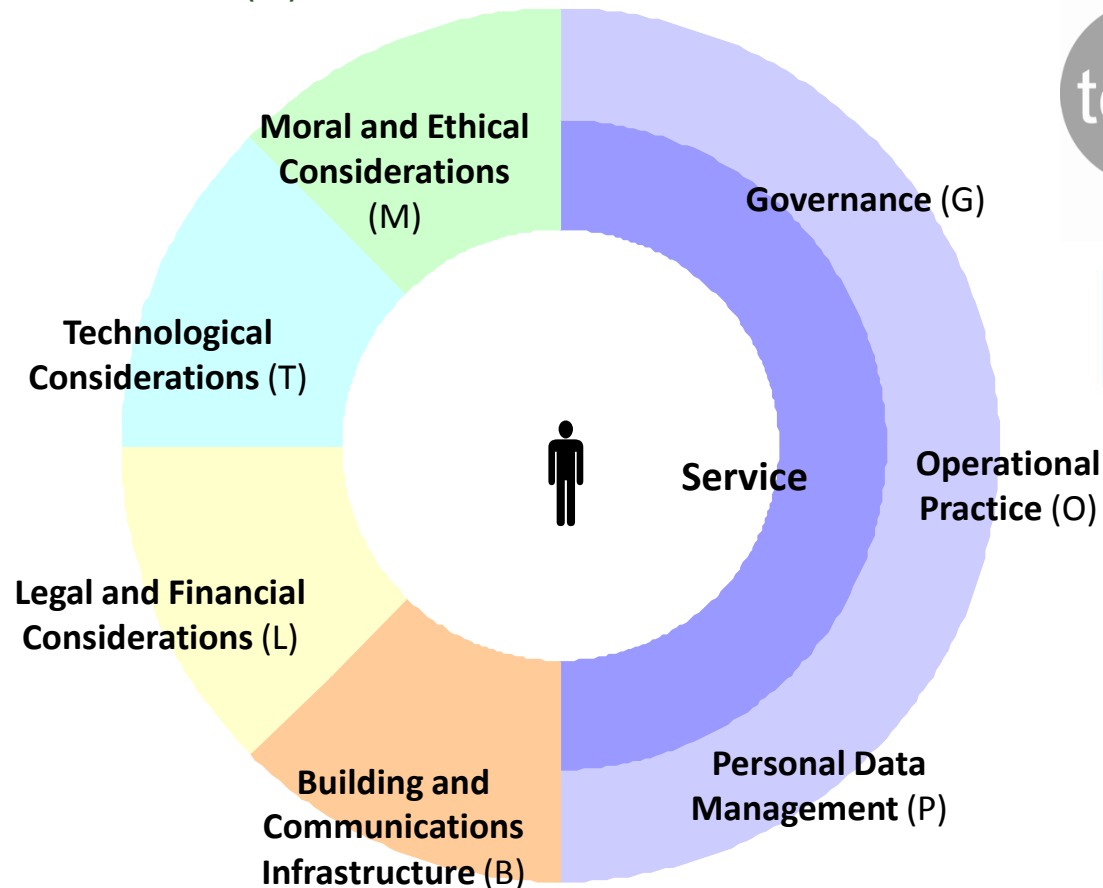
The means by which technologies and related services at a distance are accessed by or provided for people and/or their carers at home or in the wider community, in order to facilitate empowerment or the provision of care and/or support in relation to their health and well-being.

## Telehealth

The means by which technologies and related services at a distance are accessed by or provided for people and/or their carers at home or in the wider community, in order to facilitate their empowerment, assessment or the provision of care and/or support in relation to needs associated with their health (including clinical health) and well-being.



# Draft Telehealth Code of Practice Framework (v2)



# Technological Context

- Vital signs (blood pressure; blood oxygen; blood sugar; INR; weight; lung function; etc.)
- Activity within home (chair, bed, room occupancy; dwelling and room entry / exit; level / frequency of activity; medication compliance, etc.)
- Activity outside the home (smart devices)
- Issues around
  - Nature of interaction with user
  - Degrees of intrusion
  - Surveillance and impact on privacy
  - Crucial matter of consent
  - Data / information transfer
  - Information as a by-product (c/s smart metering)
- How should we view treatment of health and personal data?



# Health and Personal Data

- What is personal data? Per BCS The Chartered Institute for IT = *Data about ourselves that we may wish to keep private.*
- What is health data? Per EC (draft) = *Personal data that have close link with the description of the health status of a person.*
- Privacy is an issue
  - tension: privacy versus need for information for diagnosis and treatment
  - problem: increasing data = greater risk of privacy breaches
- Matter of ownership is unresolved / uncertain ... (per ICO)
  - “generally accepted that where personal information is gathered by an organisation, that information is the property of the organisation concerned” though subject to requirement of the Data Protection Act, but
  - ... “the issue of who should have control over the personal information is not always clear”



# Our Challenge

Our challenge! To evolve criteria for collection, storage, sharing, etc. of data that relate to telehealth ... to safeguard and ensure an appropriate degree of protection / personal control of our health data.

- Privacy will be eroded if ownership / control not retained by (assigned to) person / service user
- ... and greater onus on process of consent to gather and use health and personal data
- ... plus greater onus on service provider to follow strict guidelines on data collection / storage, etc. Key reference points = BCS Personal Data Guardianship Code / ICO ... following principles of good data governance ... (PTO)



# Some Principles

- **Visibility:** People's right to be informed / have access to data ... to correct it if it's wrong
- **Accountability:** Collection of relevant data only (and for a specific purpose)
- **Consent:** People to be given 'as much control as possible' with their 'explicit consent' being necessary where use is made of (or planned in relation to) sensitive data
- **Access:** Need for audit trail – so that it is clear who has had access and for what purpose (link to 'glass box')
- **Stewardship:** Duty of care / protection of data. Accompanied by regular risk assessments (of data loss, privacy breaches)
- *All* of heightened importance as our telehealth services gather more and more personal data ... and needing to be recognised to avoid e.g.



# **SOUTHWARK COUNCIL RECEIVES WARNING OVER DATA BREACH**

**Computer and papers containing thousands of people's personal information were discovered in a skip, says Information Commissioner's Office**

Southwark council breached the Data Protection Act after it left an unencrypted computer and papers containing sensitive information on 7,200 people in one of its buildings when it was vacated, which were then disposed of by the building's new tenant, the Information Commissioner's Office (ICO) has said.

The local authority vacated the building in December 2009, but the breach was reported in June of this year shortly after the information was found in a skip. The information stored on the computer and the papers included details of peoples' names and addresses, along with other information relating to their ethnic background, medical history and any past criminal convictions.

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# Thank You!



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