eHealth Workshop
25-26 April 2013
Middlesex University
London, UK
http://goo.gl/tgDaf

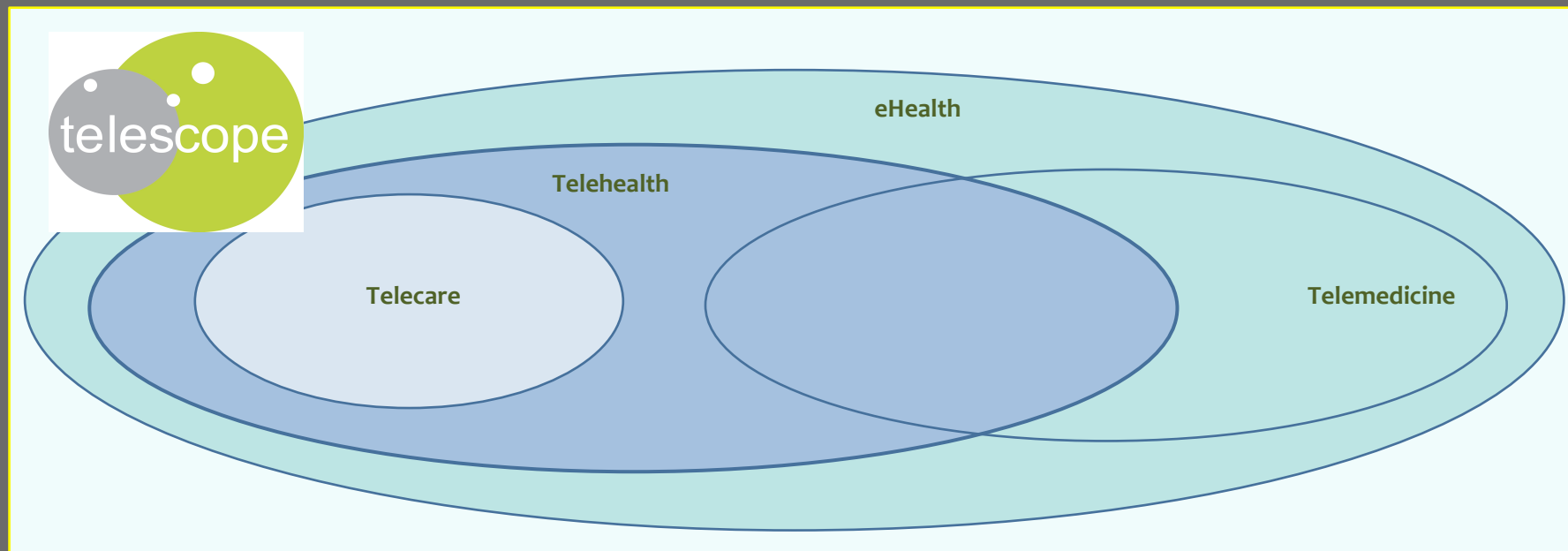2013 Middlesex University Seminar
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The Ethics of Telehealth Services:
A Code of Practice

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1

What is Telehealth? How does it fit?

Telehealth is [per TeleSCoPE project]... the means by which technologies and related services concerned with health and wellness are accessed by or provided at a distance in order to facilitate the empowerment, assessment or the provision of care and/or support for people and/or their carers (at home or in the wider community).

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eHealth and Telehealth:
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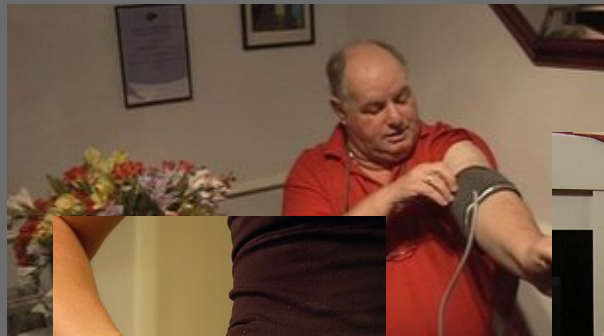# What Kinds of Services and Technologies?

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All pointing to fact that our health agenda (and that of the European Commission) is broad and relates to a variety of services and technologies ...

European Perspective Evolving

Now … 'eHealth' rather than telemedicine
⇨ **Clinical complemented by public health perspective**
⇨**Responding to widening range of initiatives**
⇨ **Responding to ambivalent evidence around cost savings around chronic conditions**
⇨ **Telehealth beginning to be 'recognised'**
⇨ **Echoed in TeleSCoPE project perspective … European CoP for Telehealth Services**

Context:
European eHealth Action Plan

⇨ **Building trust in eHealth / telehealth …
for different stakeholders**

⇨ **Improving chronic disease management**

⇨ **Developing prevention and health promotion practices**

⇨ **Redesigning delivery of care … away from 'top-down' approaches**

⇨ **Recognising patients' rights**

⇨ **Supporting access for / empowerment of all citizens**

… so why the change in perspective?

European Perspective:
Why the change?

⇨ **Impact of eHealth Task Force report recommending …**

- **A new legal basis for health data**
- **'Beacon group' of Member States and regions committed to open data and eHealth**
- **Support for health literacy**
- **Use of the power of data**
- **Re-orientation of EU funding and policies**
- **Changes in service paradigms**

eHealth Task Force Report

Redesigning health in Europe for 2020
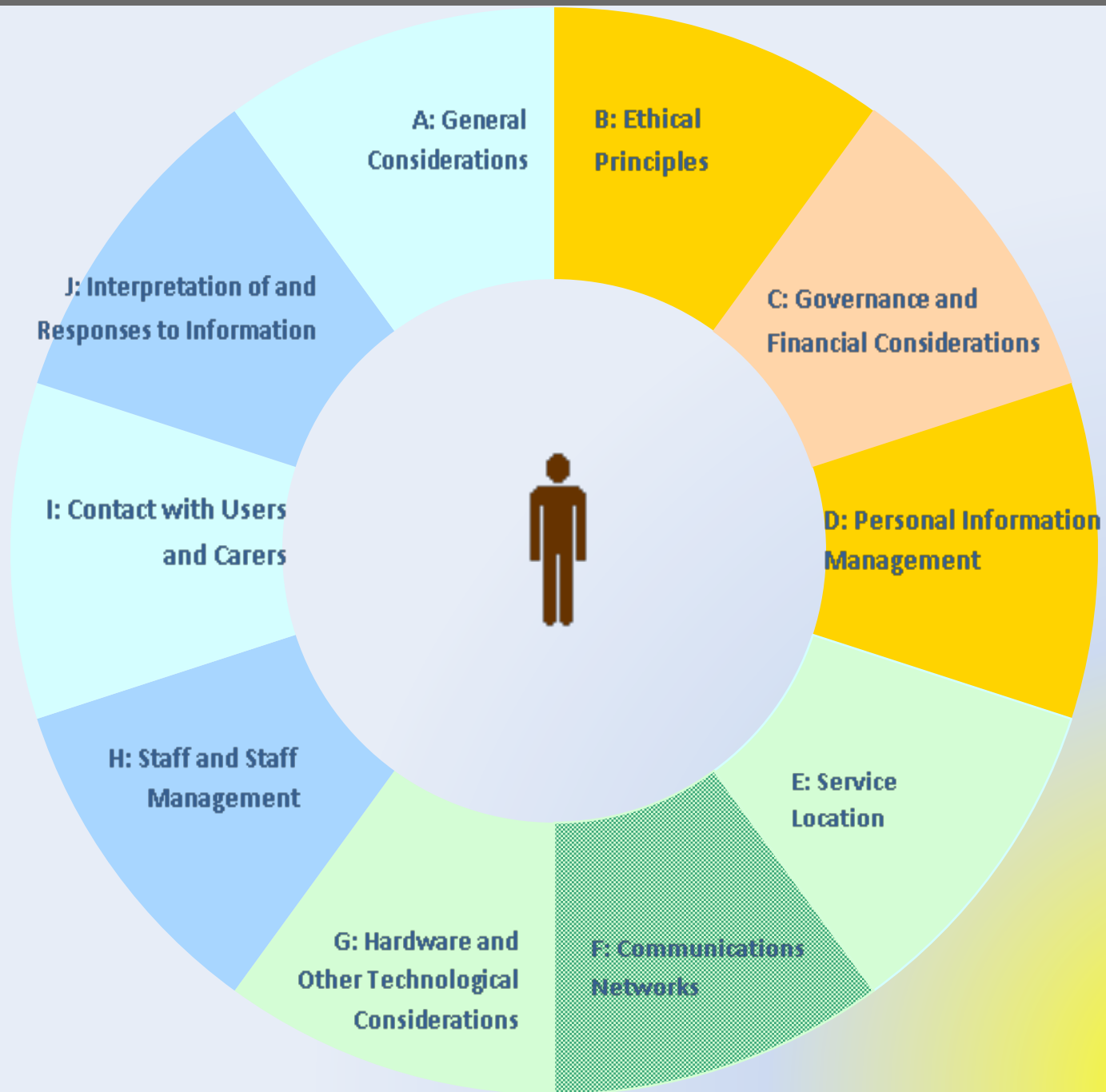
European Perspective: Why the change?

⇨ **Impact of eHealth Task Force report …**
⇨ **Power of European policy perspectives around inclusion and citizenship**
⇨ **Recognition of 'other' health crises … not just chronic conditions of older people, but also younger people (obesity, diabetes) – problems for the future!**
⇨ **Recognition of importance of health gains as great as cost savings**

eHealth Task Force Report

Redesigning health in Europe for 2020

That was the Context:
What About the Ethics?

⇨ **European Group on Ethics in Science and New Technologies (1999) main focus …**
Privacy, Confidentiality, Trustworthiness, Access – but absent are pointers to autonomy and choice (except laterally by reference to private life, *personal* health data and rights of *citizens*)
⇨ **MF / DR (book chapter) looked specifically at autonomy, linked with personal choice as an ethical principle …**
but this may, in part, have been reaction to what was seen as the suppression of autonomy as a consequence of top-down service provision
⇨ **Autonomy and personal / citizen perspectives have strongly impacted on the European Code of Practice for Telehealth Services**

European Code of Practice for Telehealth Services: Framework

A: General Considerations

B: Ethical Principles

C: Governance and Financial Considerations

D: Personal Information Management

E: Service Location

F: Communications Networks

G: Hardware and Other Technological Considerations

H: Staff and Staff Management

I: Contact with Users and Carers

J: Interpretation of and Responses to Information

European Telehealth Services Code of Practice: Ethical Sampler (1 to 6)!

- ❖ **Inclusive (all ages)**
    - ❖ **All ages**
    - ❖ **All needs**
    - ❖ **All technologies … including design / interoperability**
- ❖ **Bottom up**
    - ❖ **Health *and* well-being**
    - ❖ **User access to / ownership of health and personal data**
- ❖ **Clinical *and* public / preventative health**
- ❖ **Concerned with lifestyles as much as 'treatment'**
    - ❖ **Tends towards self-management**
- ❖ **Six 'Ethical Principles' clauses link to others … notably around consents, manner of relating to users (and carers), etc.**

European Telehealth Services Code of Practice: Ethical Principles

B1	Services shall have an up to date mission statement that is founded on sound ethical principles.	The mission statement shall be posted on the website.
	A mission statement might usefully include attention to the way in which service users and carers are empowered through the way that service choices are proffered and their views are taken into account. The mission statement shall be dated.	

European Telehealth Services Code of Practice: Ethical Principles

B2	Services shall ensure that staff and Directors are transparent about and avoid, as far as possible, conflicts or potential conflicts of interest that relate to their involvement and/or shareholdings. *Such conflicts of interest might include shareholdings or official positions held in companies that are closely associated with the service or with which the service has significant dealings. These shall be disclosed and included in an up to date and publically available register of interests. The information posted shall be dated and renewed at least annually.*	The names of directors and senior management staff shall be posted on the website.

European Telehealth Services Code of Practice: Ethical Principles

B3	Services shall not market their wares by preying on fear (e.g. portraying users as potential victims or sufferers), omitting important or giving misleading or unsubstantiated information. *The vulnerability of users and carers is such that many will be at higher risk in relation to their health and well-being. Neither the extent of that risk, nor the anticipated benefits of telehealth be exaggerated or over-emphasised.*	

European Telehealth Services Code of Practice: Ethical Principles

telescope

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	The vulnerability of *at higher risk in rel* *Neither the extent* *telehealth be exag*	

Lifeline Medical Alert Service

$0 – No equipment to buy

$0 – No long term contract

$0 – No hidden fees

Philips Lifeline USA – Website 24.4.2013

1 2 3 4 5 6

European Telehealth Services Code of Practice: Ethical Principles

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Vivago (France / Finland) – Website
24.4.2013
1 2 3 4 5 6

European Telehealth Services Code of Practice: Ethical Principles

B4	Services shall be made available in a manner that offers informed choice to users and carers.	
	Informed choice means that users and carers must receive timely, clear and comprehensive information; they must be clearly aware of service options; service operation; arrangements for termination of or withdrawal from the service; and all applicable charges and costs – including those that apply when devices are supplied by users and carers themselves.	
	Informed choice also means that, in communicating information, proper attention is given to the needs of users and carers with e.g. hearing loss, sight loss, physical or cognitive impairments (see Appendix C).	

European Telehealth Services Code of Practice: Ethical Principles

B5	Services shall, in all aspects of their operation, give due consideration to the views, opinions and choices of service users and carers. *The views of the user shall take precedence over those of carers except for young children or e.g. where there is substantial dependency arising e.g. out of cognitive impairment or mental illness.*	

European Telehealth Services Code of Practice: Ethical Principles

B6	All staff and volunteers engaged by services shall maintain informed, empathetic and non-judgemental approaches in their dealings with users and carers.	

And Finally! Technologies seen as the constant 'presence of others' … an element of which relates to human care

⇨ **Move from autonomy to heteronomy? … or does configuration of the technology facilitate retention of autonomy?**
⇨ **Anthropomorphic element to way people see / interact with technologies … because they are the 'human' link – guaranteeing, in fact, the 'presence of others'**
⇨ **Importance of the effects of technologies on users**

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34

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Tunstall UK – Website 24.4.2013

35

Thank you!
Diolch yn fawr

Thank You!

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