



COMITÉ PERMANENT DES MÉDECINS EUROPÉENS
STANDING COMMITTEE OF EUROPEAN DOCTORS



Session 2 - How do end-users contribute to digital health innovations?

- Better communication and coordination of care for health professionals -



ICT4Life Final Conference
Meeting the Challenges of Digital Health
Innovation for Integrated Care in the EU

18 October 2018, ICAB – Business & Technology
Incubator, Rue des Pères Blancs 4 | Brussels

Annabel Seebohm, LL.M.



Declaration of Interest

- I declare the following interests: none
- Except being employed by the Standing Committee of European Doctors (CPME).



Introducing CPME

- CPME represents national medical associations across Europe. We are committed to contributing the medical profession's point of view to EU institutions and European policy-making through pro-active cooperation on a wide range of health and healthcare related issues.
- CPME believes the best possible quality of health and access to healthcare should be a reality for everyone. To achieve this, CPME promotes the highest level of medical training and practice but also the provision of evidence-based, ethical and equitable healthcare services.



Better communication and coordination of care

- It is assumed that integrated care leads to better communication and coordination while fostering patient autonomy.
- However, any application in integrated care needs to provide the evidence as to safety, effectiveness, costs and privacy.
- While using integrated care models, the following principles are paramount:
 - Confidentiality
 - Patient Autonomy
 - Equity and Access



Confidentiality and Team Work

- Doctors and other professions working in a physician led team are generally bound to the same scope of confidentiality that physicians are bound to.
- Breaches are sanctioned by professional regulation, criminal, labour and contract law.
- What happens to other professions/care givers working independently in integrated care scenarios: Which scope of confidentiality applies? Do tiered access rights help?



COMITÉ PERMANENT DES MÉDECINS EUROPÉENS
STANDING COMMITTEE OF EUROPEAN DOCTORS



Confidentiality and Team
Work

1: Patients or proxy decision-makers should expressly consent to having health and personal data shared in integrated care models – pending checks on data minimization and purpose limitation – only to the extent necessary.



Patient Autonomy, Consent and Re-Use of Data

- Respect patient autonomy.
- This principle finds its clinical and “digital” expression in the obligation to seek informed/express consent.
- To interfere with the right to privacy and self-determination is to disrespect autonomy. Privacy is regulated by the GDPR.
- What happens if integrated care models reuse data for research purposes other than consented to?
 - The GDPR provides for a research privilege enabling the re-use of data for secondary purposes without concrete safeguards or guidance.
 - The [WMA Declaration of Taipei](#) recognises big data research scenarios by referring to “multiple and indefinite uses” and relies on consent adapted to real life scenarios using the oversight of independent ethics committees.



Confidentiality and Team
Work

1: Patients or proxy decision-makers should expressly consent to having health and personal data shared in integrated care models – pending checks on data minimization and purpose limitation – only to the extent necessary.

Patient Autonomy,
Consent and Re-Use of
Data

#2: Integrated care models reusing data for research purposes other than consented to need clear governance structures including ethical oversight.



Equity and Access

- Equity in health can be defined as the absence of socially unjust or unfair health disparities.
- While introducing integrated care models questions arise as to:
 - Who has access?
 - Are integrated care models just cheap substitutes?
 - Do integrated care models serve equity or the development of tiered healthcare systems?



Confidentiality and Team Work

1: Patients or proxy decision-makers should expressly consent to having health and personal data shared in integrated care models – pending checks on data minimization and purpose limitation – only to the extent necessary.

Patient Autonomy, Consent and Re-Use of Data

#2: Integrated care models reusing data for research purposes other than consented to need clear governance structures including ethical oversight.

Equity and Access

#3: Integrated care models should facilitate equitable access to high quality care.



Practical Questions

- Given integrated care models monitor 24/7, how can we make sure that each profession receives all relevant data while avoiding alarm fatigue?
- The data collected are not of the same relevance to all participants in the model. Can augmented intelligence help in adapting data monitoring?
- What happens to non-relevant data? Can non-relevant anonymous data (e.g. location and mobility data) be abused for commercial, political or other purposes?
- Who is liable if processes in the integrated model go wrong?
-



Confidentiality and Team Work

1: Patients or proxy decision-makers should expressly consent to having health and personal data shared in integrated care models – pending checks on data minimization and purpose limitation – only to the extent necessary.

Patient Autonomy, Consent and Re-Use of Data

#2: Integrated care models reusing data for research purposes other than consented to need clear governance structures including ethical oversight.

Equity and Access

#3: Integrated care models should facilitate equitable access to high quality care.

Practical Questions

#4: In integrated care models clear rules need to apply based on a sound ethical basis.



Confidentiality and Team
Work

1: Patients or proxy decision-makers should expressly consent to having health and personal data shared in integrated care models – pending checks on data minimization and purpose limitation – only to the extent necessary.

Patient Autonomy,
Consent and Re-Use of
Data

#2: Integrated care models reusing data for research purposes other than consented to need clear governance structures including ethical oversight.

Equity and Access

#3: Integrated care models should facilitate equitable access to high quality care.

Practical Questions

#4: In integrated care models clear rules need to apply based on a sound ethical basis.



Thank you!

- For more information, please contact:
Annabel Seebohm
CPME Secretary General
Tel.: +32 2 732 72 02
Fax: +32 2 732 73 44
e-mail: annabel.seebohm@cpme.eu
- For more information about CPME, please consult: www.cpme.eu