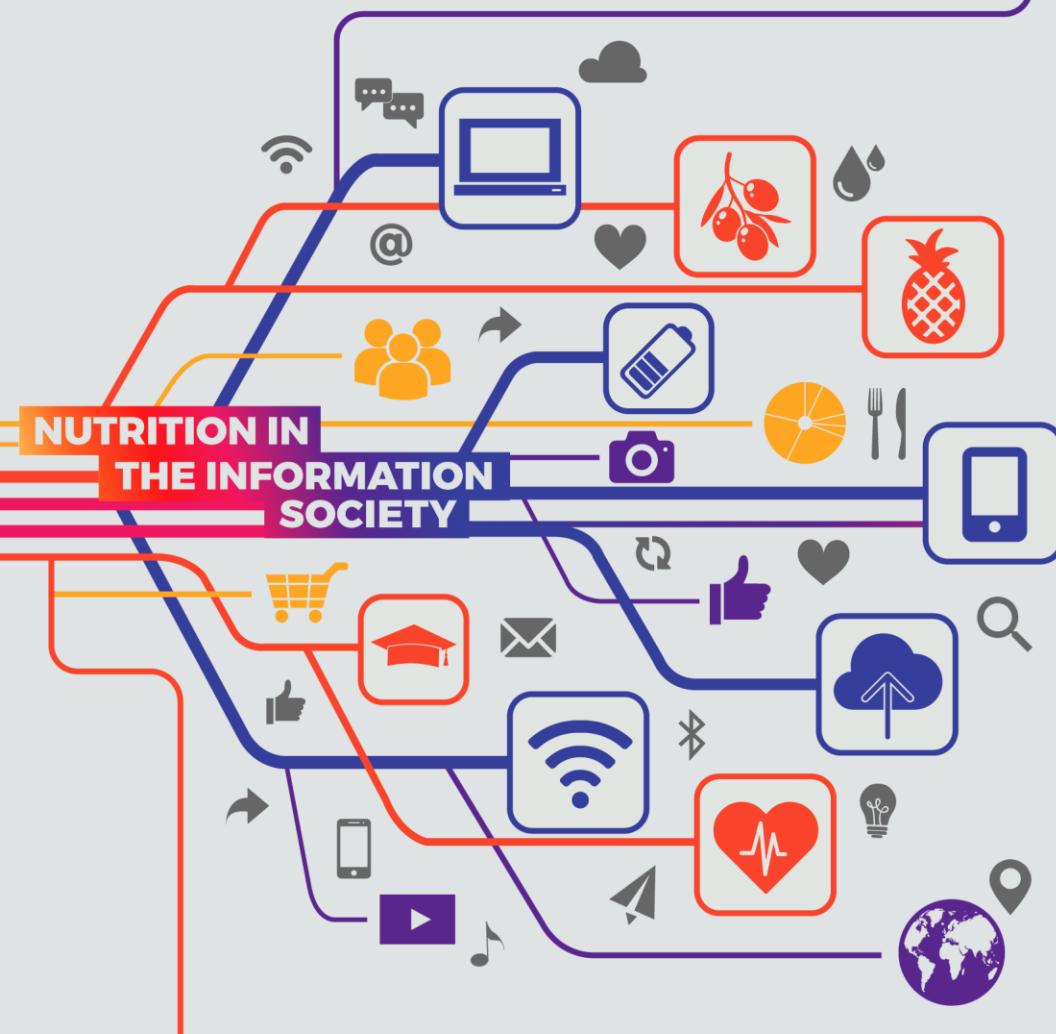




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# The Power of Digital Solutions for Health & Disease Management

Sascha Marschang  
Director, Membership & Operations  
European Public Health Alliance



# TABLE OF CONTENTS

## EPHA

Europe, e/mHealth,  
opportunities &  
concerns

About us



Inclusive Digital Health  
Campaign

# Disclosure

- I have no actual or potential conflict of interest in relation to this presentation / programme.



## OUR MEMBERS



fighting heart disease  
and stroke  
european heart network



## NATIONAL



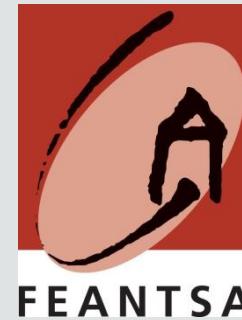
## FEDERATIONS



## EUROPEAN



## NGOs / CHARITIES



## ASSOCIATIONS



## REGIONAL



# WHO ARE WE?

MISSION

VISION

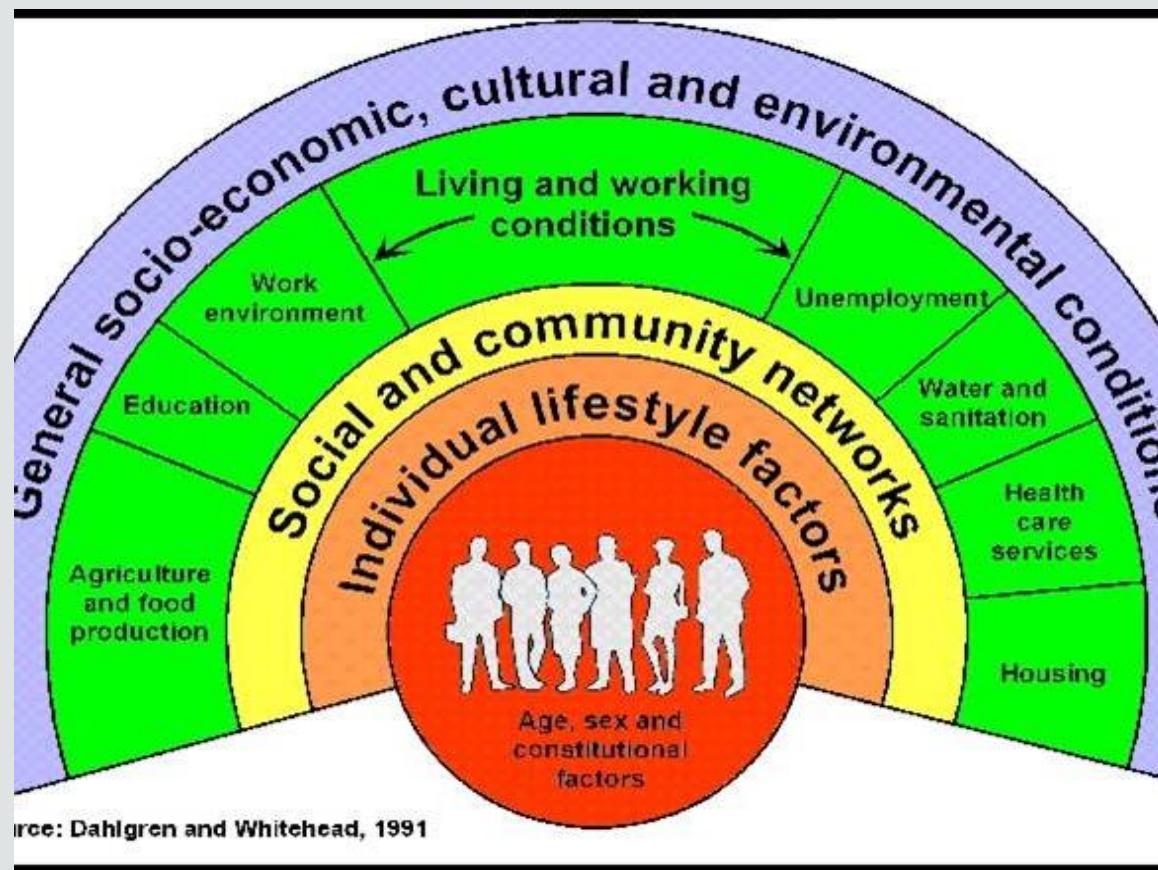


- Bring together the public health community
- Provide leadership and facilitate change
- Build capacity to deliver equitable solutions
- **Improve health and reduce inequalities**

- A Europe with universal good health & wellbeing, where **all have access to a sustainable, high quality health system**
- A Europe whose policies & practices contribute to health, **within and beyond its borders... SDGs?**

# Health in all Policies approach



# Common challenges...

- Ageing European society
- Growing burden of chronic, non-communicable diseases
- More (health) inequalities within and between countries, amplified by the economic crisis, unemployment, globalisation, increased migration, etc.
- Barriers to access to healthcare
- Cross-border health threats, including AMR, infectious diseases (Zika, Ebola, etc.)
- Squeeze on public sector resources
- Health worker shortages
- Environmental deterioration
- (...)

ALWAYS  
CHALLENGE  
The Old Ways  
purehappylife.com



## ... placing a burden on health system sustainability

# Select EU initiatives & legislation: eHealth / data

- eHealth Action Plan 2012-2020 – Innovative healthcare for the 21<sup>st</sup> century
- eGovernment Action Plan [2016]
- EC COM on “effective, accessible & resilient health systems” [2014]
- Mid-term review of Digital Single Market [2017]
- EIP on Healthy & Active Ageing, Active & Assisted Living Joint Programme
- eHealth Network & supporting Joint Action – patient summaries and ePrescription = use cases of cross-border patient data exchanges [2018], future development of European EHR
- Study on Big Data in Public Health, Telemedicine and Healthcare [2016]
- Directive 2011/24/EU on application of patients’ rights in X-border healthcare
- General Data Protection Regulation (GDPR) – effective 25 May 2018
- ePrivacy Regulation – upcoming
- REG on electronic identification [2014], DIR on security of network and information systems [2016], etc...
- Project funding, e.g. Horizon 2020, IMI, Chain of Trust, ENS4Care



# eHealth Stakeholder Group (2012-14, 2016-18)

- 4 reports released in 2014 - “Health inequalities and eHealth”, “Patient access to EHR”, “Telemedicine deployment”, “Interoperability”
- 2017-18 reports incl. “eStandards” & “Side effects / shifting balances”

Digital Single Market

NEWS ARTICLE | 26 April 2016

## New members eHealth Stakeholder Group have been selected

Following a call for expression of interest, the European Commission has selected 30 members to participate in its eHealth Stakeholder Group 2016-2018. Members of the group are expert representatives of European umbrella organisations active in the eHealth sector.



As part of the EU's commitment to engage stakeholders in public policy making, the eHealth Stakeholder Group is expected to contribute to the development of legislation and policy related to eHealth. Policy areas of

Health inequalities and eHealth

Report of the eHealth Stakeholder Group

Final version  
21 February 2014

Issue Leader: Sasha Marschang, EPHA

# Estonian Presidency [Jul – Dec, 2017]


 Council of the European Union  
 Brussels, 28 November 2017  
 (OR. en)  
 14078/17  
 SAN 399  
 TELECOM 272  
 DATAPROTECT 177

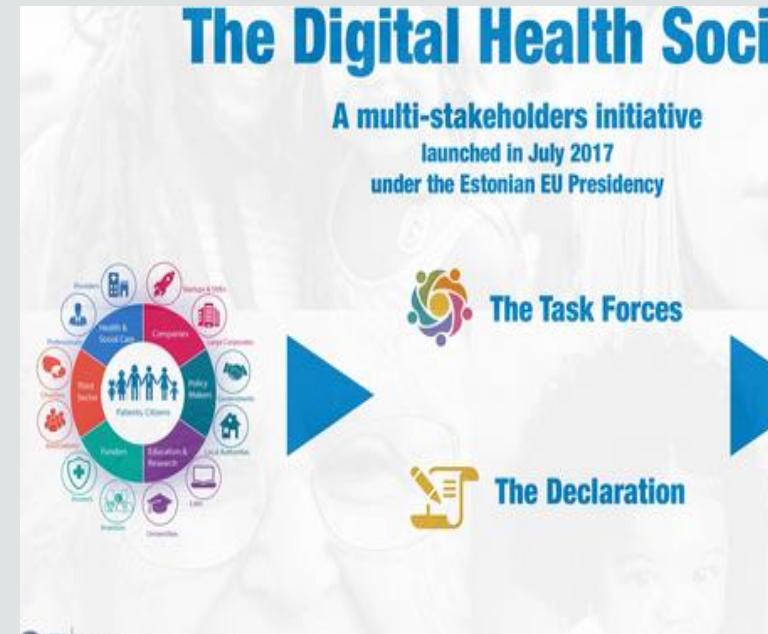
**NOTE**

From: General Secretariat of the Council  
 To: Council  
 No. prev. doc.: 14076/17 SAN 398 TELECOM 271 DATAPROTECT 176  
 Subject: Employment, Social Policy, Health and Consumer Affairs Council meeting on 8 December 2017  
 Draft Council conclusions on Health in the Digital Society - making progress in data-driven innovation in the field of health  
 – Adoption

1. On 24 November, the Permanent Representatives Committee examined the draft Council conclusions as set out in the Annex to document 14076/17.  
 2. The Permanent Representatives Committee decided to submit the draft conclusions to the Council (EPSCO) for adoption at its session on 8 December 2017.  
 3. The Council is therefore invited to adopt the draft conclusions set out in the Annex to this document and to decide to publish them in the Official Journal of the European Union.

**The Digital Health Society**

A multi-stakeholders initiative  
launched in July 2017  
under the Estonian EU Presidency



**The Task Forces**

**The Declaration**

**Actions & Projects**

**Events & workshops**

# Digital Health and Care



TRANSFORMATION OF HEALTH AND CARE IN THE DIGITAL SINGLE MARKET - Harnessing the potential of data to empower citizens and build a healthier society

## European health challenges

- Ageing population and chronic diseases putting pressure on health budgets
- Unequal quality and access to healthcare services
- Shortage of health professionals

## Potential of digital applications and data to improve health

- Efficient and integrated healthcare systems
- Personalised health research, diagnosis and treatment
- Prevention and citizen-centred health services

## What EU citizens expect...

90% agree

To access their own health data (requiring interoperable and quality health data)

80% agree

To share their health data (if privacy and security are ensured)

80% agree

To provide feedback on quality of treatments

## Support European Commission:

1

### Secure access and exchange of health data

#### Ambition:

Citizens securely access their health data and health providers (doctors, pharmacies...) can exchange them across the EU.



#### Actions:

- eHealth Digital Service Infrastructure will deliver initial cross-border services (patient summaries and ePrescriptions) and cooperation between participating countries will be strengthened.
- Proposals to extend scope of eHealth cross-border services to additional cases, e.g. full electronic health records.
- Recommended exchange format for interoperability of existing electronic health records in Europe.



LETTER 2014/0147 (C) 2014

2

### Health data pooled for research and personalised medicine

#### Ambition:

Shared health resources (data, infrastructure, expertise...) allowing targeted and faster research, diagnosis and treatment.



#### Actions:

- Voluntary collaboration mechanisms for health research and clinical practice (starting with 'one million genomes by 2022' target).
- Specifications for secure access and exchange of health data.
- Pilot actions on rare diseases, infectious diseases and impact data.



3

### Digital tools and data for citizen empowerment and person-centred healthcare

#### Ambition:

Citizens can monitor their health, adapt their lifestyle and interact with their doctors and carers (receiving and providing feedback).



#### Actions:

- Facilitate supply of innovative digital-based solutions for health, also by SMEs, with common principles and certification.
- Support demand uptake of innovative digital-based solutions for health, notably by healthcare authorities and providers, with exchange of practices and technical assistance.
- Mobilise more efficiently public funding for innovative digital-based solutions for health, including EU funding.

#DigitalSingleMarket #DigitalHealth @eHealth\_EU @EU\_Health



## European activities impacting mHealth:

- Green Paper on mHealth & Staff Working Paper on applicable legal framework to lifestyle & wellbeing apps [2014]
- Code of Conduct on privacy for mHealth apps (industry-led)
- mHealth assessment Guidelines
- Medical Devices / In Vitro Diagnostic MD Regulations [2017]
- EU Consumers' Rights DIR, eCommerce rights, etc....

## La santé numérique, lente à la détente

Pendant six mois, le gouvernement fédéral a financé le projet « Mobile Health » : les huit derniers projets sont présentés vendredi devant l'Inami, sans l'assurance d'être renouvelés.

**C**arde, 45 ans, est diabète depuis 10 ans. Ses traitements et son régime sont stricts. Il prend quatre doses d'insulines par jour. Parfois plus. Pensez à les prendre pour atténuer les vertiges physiologiques n'est pas une habitude qu'il a acquise. « J'ai toujours été un peu bas du poing », dit-il. Mais il a commencé à prendre de l'aspirine. « Je suis un peu à l'opposé de l'aspirine », dit-il. Mais il a commencé à prendre de l'aspirine. « Je suis un peu à l'opposé de l'aspirine », dit-il.

« Les patients se sentent moins seuls et adaptent leur traitement plus rapidement »



Une application sur son smartphone permet de mesurer sa glycémie, son poids, sa tension artérielle... De quoi aider sa santé.

Le docteur a aussi mis en place des séances-consultations. « Toutes les deux semaines, nous questionnons le patient pour parler des infections récentes et faire ainsi le point. Au départ, on pensait que les patients seraient également d'accord avec ça », dit *Big Brother*. Mais après avoir mis un sondage papier aux magasins intérieurs des résultats nous ont surpris : globalement, les patients appréciaient ce suivi et se sentaient assurés de mieux et adaptées plus rapidement leur traitement en fonction des conseils de médecins. »

Tous les 24 projets-pilotes sont, il y a d'autres affections que le diabète : maladies cardiovasculaires, sucre de sucre mentale ou *dependance*. Prendre six mois, le

### EXERCICE

### de validation n

« Grâce à des applications et des opérateurs mobiles, les patients peuvent suivre et faire suivre leur santé », observe la ministre de la Santé Maggie De Block (Open-VLD). Basé la veille du « Plan d'action e-santé 2013-2018 », réactualisé en 2015, elle a lancé fin juillet 2016 un appel à projets sur les soins de santé connectés et mobiles, pour une période de six mois. Sur les 98 projets reçus, 15 ont été sélectionnés.

santé connectée au sein du système de soins actuel. Dans ce cadre, plusieurs acteurs de soins ont mis leurs efforts : Metalab, Inforéaux, services de soins à domicile, etc. Deux tiers des projets sont déjà passés devant les experts réunis à l'Inserm depuis début février. Le but dernier sera présentation vendredi. « On va tirer les leçons du projet et nous essayer d'améliorer avec l'ensemble de réalisations », qu'il faut encore mettre en place dans les mois à venir, précise Éric Van den Hulst, chef du service de l'innovation.

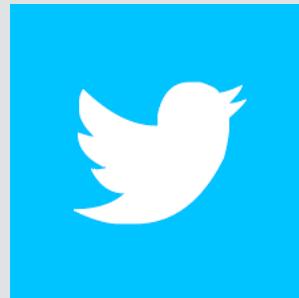
classant que l'application est conforme à la normativité européenne en la matière. Fait, l'inter-opérabilité, soit l'efficacité des logiciels pour communiquer et échanger directement les informations au sein d'un réseau. À part de ça seulement, le projet pourra être considéré « fonctionnel ». Mais à ce jour, seuls deux des 24 projets ont déjà une certification CE. « Les projets pilotes lancés courant 2012 utiliseront d'illustres applications de santé, allant de l'autogestion à la téléconsultation en passant par l'utilisation d'applications de santé. » Phénoménal élément.

[Article from *Le Soir*, 23 Feb 2018, Belgium]

# How to integrate mHealth into the health system?

- 24 pilot projects testing mHealth solutions within the current HC system in BE (hospitals, insurance providers, home care, etc.)
- The technology is available, but important legal and financial barriers remain
- How to scale up pilots in the long term?
- “Evaluation pyramid”: Do solutions conform to EU norms (CE mark, GDPR), are they sufficiently interoperable?

# Big Data = Big Brother?



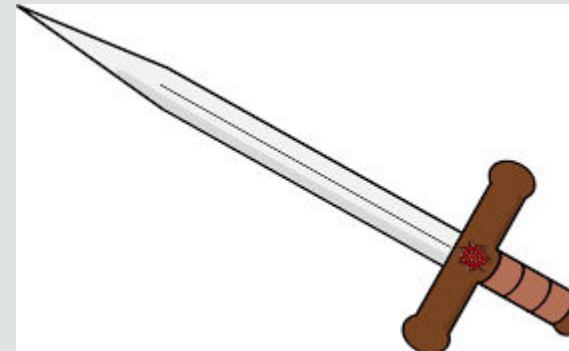
## A critical stance....

- Cyberbullying & aggression
- Reputational damage / denunciation
- Profiling
- Data mining
- Excessive marketing
- Fake news
- Fraud
- Identity theft
- Increased stress / depression
- Online addiction
- Extreme political propaganda
- From liberation to control?



“By using digital solutions, such as wearables and mHealth apps, citizens can actively engage in health promotion and self-management of chronic conditions. This in turn can help control the rising demand for health and care. Digital tools hold great potential to disseminate scientific knowledge in an easily accessible form, so as to help people stay in good health – thus preventing them from turning into patients.”

- EC COM(2018) 233 final, p.11

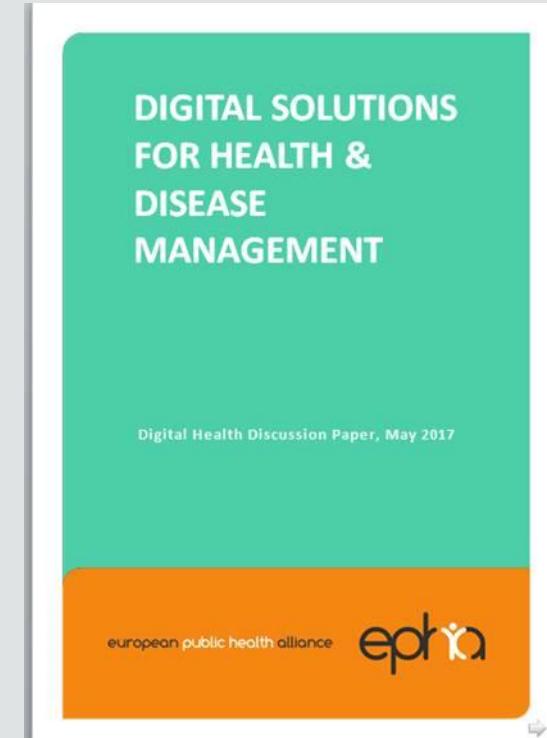


“Big data in health may come from a variety of sources including social media, physical activity trackers, electronic health records, insurance claim databases, patient registries, health surveys and observational studies, provided that the requirements of the GDPR are complied with”.

- EC SWD(2018) 126 final, p.36

# EPHA Digital health paper, May 2017

- Pros & cons for end users, incl. ordinary people, patients, carers, professionals
- Snapshot of experience in members' areas:
  - Diabetes
  - Cardiovascular
  - Cancer
  - Mental health
  - Healthy Ageing
  - Disadvantaged groups
- Universal vs specific benefits
- How do they make people *feel*?
- Does not specifically discuss data protection



# Special role for mobile solutions?

- “eHealth on-the-go”, accessible, tangible, inexpensive, practical
- Multi-functional: Internet, texting, phone, camera, video, GPS, scanner, sensors, avatars, games, voice recognition, etc.
- Appetite for new technology is unlikely to fade away
- Offering new ways of (self-)engagement: communication, information, learning, collecting / storing / analysing / monitoring data
- Quickly taken up, quickly abandoned? Must be user-friendly, simple
- More knowledge – more need for guidance from HCPs?



# Managing health trajectories

- Supporting life episodes, from birth to end-of-life care
- Prevention & health promotion, diagnosis, disease management, follow-up
- No “one size fits all”

A ces différents stades du parcours de santé des personnes correspondent **des besoins et des capacités différents** qui dépendent à la fois du niveau d'inclusion sociale des personnes concernées, de leurs ressources personnelles, de la place qu'occupe la santé dans leur propre échelle de valeurs, de la gravité des pathologies dont elles souffrent et de l'intensité de leur implication personnelle dans la gestion de leur vie avec la maladie (Le CISS/France Assos Santé, *Note de position commune sur le numérique en santé*, 2015)



# General benefits



- Involvement: more ownership & (co)-responsibility = empowerment?
- Greater control: routine tasks & administration (e.g. managing appointments, measuring vital signs), early detection, etc.
- Patient safety: remote monitoring, avoiding duplication, medication errors & drug interactions, better treatment adherence, ...
- Improving health literacy: 24/7 access to information, global source of information, tailored services & tools
- Direct & more targeted communication between patients/carers and healthcare professionals: guidance, overcoming isolation, building trust, empathy...
- Boosting prevention & awareness-raising (SMS, alerts, reminders, etc.)
- Fostering inclusion & access (e.g. excluded groups)
- Improved continuity of care – between HC settings & countries
- Enabling multi-professional collaboration & new roles



# Specific benefits: Diabetes / cardiovascular / respiratory / cancer

- Difficult seeing healthcare professionals as needed (esp. diabetes), yet many difficult decisions taken on your own, every day
- Daily monitoring & up-to-date data (blood glucose levels, blood pressure, etc.)
- Reminders (e.g., inject insulin, take pills) & automation to avoid drop-out
- Discipline: accurate documentation, timely & routine action
- Prevention & managing risk factors: encouraging & checking healthy nutrition, physical activity; smoking cessation (apps, wearables, sensors)
- Coaching & education: motivation, teleconsultations, product information...
- Continuous, real-time checks to reduce emergency admissions (e.g. Internet monitoring of implanted defibrillators)
- Follow-up, e.g. apps to improve patient adherence to rehabilitation programmes
- Survivorship care



# Specific benefits: Mental health



- Anonymous digital services help overcome stigma, shame & discrimination, give back dignity
- Tailored solutions for treating depression, mood, stress, addiction, etc.
- Real-time contact with qualified professionals at home
- V.R. simulations for overcoming (social) phobias; serious gaming
- Features adapted to mental / learning capabilities
- Beware of quality concerns & online “charlatans”
- Human connection extremely important

# Specific benefits: Older people

- Often experiencing multiple morbidities & disability, complex histories
- Potentially isolated / resigned
- Not “digital natives” - life-long habits hard to break
- In & out of healthcare, dependent on family / carers
- Technology can enable more active role in life & health
- Making it easier to see, speak, hear, move, identify objects, request help
- Longer independence (domotics / robotics, remote monitoring, AAL, etc.)
- Features & services adapted to specific needs
- Must be simple & uncomplicated



## Nutrition and diet apps

- Weight loss / nutritional goals
- Counting calories, tracking macronutrients (protein, carbs, fat)
- Database of foods
- Compatibility for people with diabetes, allergies, food sensitivities...
- Tracking physical activity / fitness levels / hydration / etc.
- Meal planning & food diaries
- Barcode scanning for product info
- Recipe storage & nutritional breakdown of meals
- Database of restaurants, matching meals with profile
- Graphs & charts to assess food habits
- Interactivity
- Costly: often, extra subscription required
- iOS vs Android features
- Limited participation of businesses
- Meaningfulness of information?



# Rivera, J. et al. (2016), JMIR mHealth & uHealth

- Rising prevalence of overweight & obesity
- Close link to many chronic diseases incl. hypertension, diabetes type 2, CVD, stroke...
- Little physical activity & sedentary behaviours
- Costly, time- and resource-intensive clinical interventions & access barriers
- Rapid market expansion for weight loss apps
- **Can clinical intervention strategies be effectively translated to mobile devices?**
- **To what extent are evidence-based strategies, health care expert involvement & scientific evaluation of apps taken into account?**

Journal List > JMIR Mhealth Uhealth > v.4(3); Jul-Sep 2016 > PMC497882



**JMIR mHealth and uHealth**  
Mobile and tablet apps, ubiquitous and pervasive computing, wearable computing and  
informatics for health

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Published online 2016 Jul 28. doi: [10.2196/mhealth.5155](https://doi.org/10.2196/mhealth.5155)  
PMID: [27480502](https://pubmed.ncbi.nlm.nih.gov/27480502/)

**Mobile Apps for Weight Management: A Scoping Review**

Monitoring Editor: Gunther Eysenbach

Reviewed by Margaret Allman-Farinelli, Francesc Saigó-Rubió, Hyeoun-Ae Park, and Emily Knight

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This article has been cited by other articles in PMC.

**Abstract**

**Background**

Obesity remains a major public health concern. Mobile apps for weight loss/management are found to be effective for improving health outcomes in adults and adolescents, and are pursued as a cost-effective and scalable intervention for combating overweight and obesity. In recent years, the commercial market for 'weight loss apps' has expanded at rapid pace, yet little is known regarding the evidence-based quality of these tools for weight control.

**Objective**

To characterize the inclusion of evidence-based strategies, health care expert involvement, and scientific evaluation of commercial mobile apps for weight loss/management.



# Findings

- Limited improvements have been made in commercial app market despite major growth
- **Major limitations**
  - Simplistic capabilities lacking personalisation to complex user needs & preferences
  - Lack of health care expert involvement during app development
  - Minimal use of evidence-based strategies for management of obesity
  - Absence of scientific evaluation of these tools
- “Most apps may not be suitable for supporting individuals with severe or complex obesity who have complex medical and self-management needs”
- “Apps tend to possess a singular focus on either the physical activity or dieting practices for weight loss. [They] do not comprehensively address the full range of cognitive, behavioural, and environmental factors that can impact a person’s ability to manage their weight over the long term”

# Many advantages

- Growing evidence of benefits
- Enabling tools to complement conventional healthcare
- Technological development & convergence is inevitable, patient/consumer demand is high
- Many different ways to engage people, can be “fun”
- Willingness to share health data is greater than concern about misuse
- Timely, accurate measurements, tailored treatment & better prevention
- Cost-effective, universal access to healthcare for all
- Supporting crucial public health functions, e.g. tackling cross-border healthcare threats (antimicrobial resistance, infectious diseases, etc.)



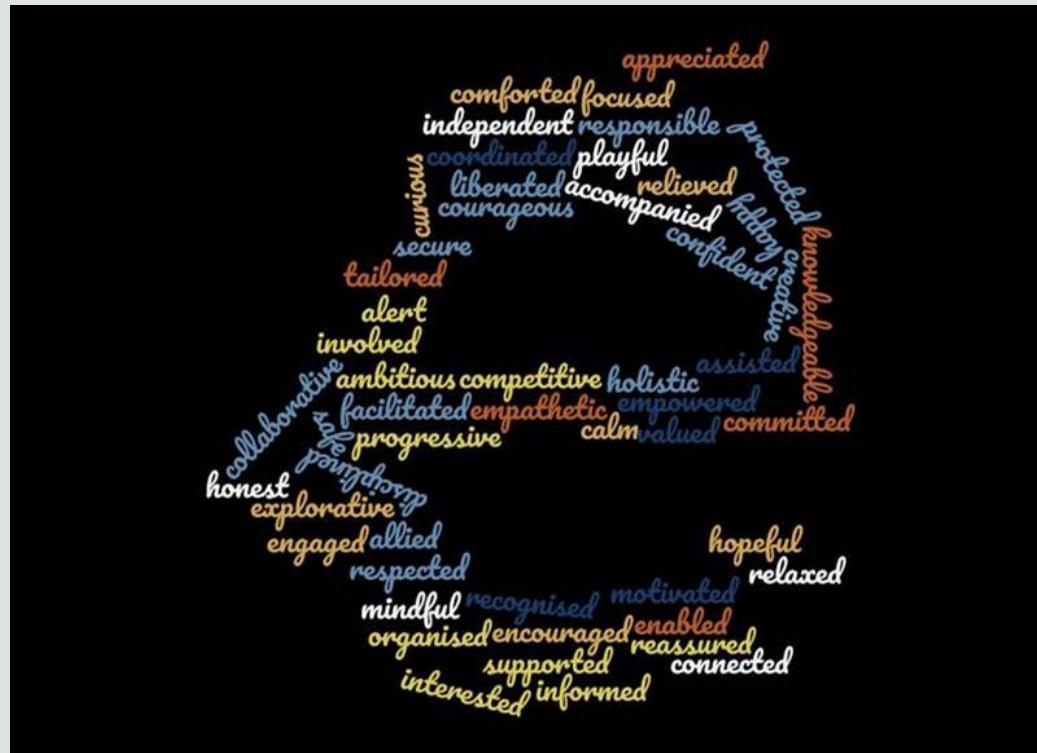
# ...but many questions remain...



- Does not *replace* face-to-face contact: health is a result of individual histories
- Need to step up eSkills & health literacy of population groups & professionals
- Availability & access are not a given (e.g., constant upgrades & upskilling)
- Data protection & privacy implications are serious - nothing is ever safe
- Quality of information, devices & software – dangers of incorrect data & use
- Self-diagnosing & self-treatment can be dangerous
- Increasingly driven by non-health actors: more data, more value for marketing
- Cons of “quantified self” & surveillance at societal level?
- Private, emotive vs commercial sphere

# Health is different: Emotion & affect are omnipresent

## Digital solutions can make you feel good [OR bad]





## So what? A few recommendations...

- Establish effective co-creation process, based on practical & health needs
- Ensure inclusive and ethical integration into health systems to improve access to healthcare
- Enhance eSkills and digital health literacy of end users
- Establish repositories of digital solutions (e.g. apps) endorsed at national and/or EU level
- Include patient safety and quality of care considerations in all initiatives
- Foster research into actual uses & outcomes of digital health

## Public system vs private market for digital solutions – are “health” and “digital health” two sides of the same coin?



Ultimately, the question is: *what kind of health system* do people in Europe want in the future?





European Public Health Alliance

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