

EHFG 2017 MEDIA ADVISORY – TODAY'S QUOTES ON KEY THEMES:

BIG DATA

The EHFG 2017 kicks off with a deep dive into Big Data and technological innovation that are fast defining the contemporary health landscape. Big data and technological innovation are opening up new opportunities for making health systems more resilient, but they have the potential to be disruptive, challenging the current stance on ethics and quality of care.

Some stakeholders see Big Data and technological innovation as a means to better monitor patients and prevent diseases, delivering better access to quality care and to alleviating the burden on health systems. Other stakeholders are raising the alarm about the risks, highlighting in particular the ability of judicial systems to keep up with rapidly advancing technological developments, and the need to have comprehensive frameworks in place to ensure that the personal data of patients and citizens are protected.

Big data is one of the four themes of the EHFG 2017. Here's what Europe's leading health policy experts are saying about it at the EHFG 2017.

“Governments need to invest in data governance systems so that data is linked but remains private and personal. Without data governance systems we cannot use data, which means we miss opportunities.”

- **Francesca Colombo**, Head of the Health Division, Directorate for Employment, Labour and Social Affairs, OECD

“The Estonian Presidency of the EU is keen on getting strong agreement from Member States to advance healthcare and make use of digital data. I hope that health ministers will give a strong political mandate to what is discussed at Gastein so we can implement them at large.”

- **Ain Aaviksoo**, Secretary General for E-services & Innovation, Ministry of Social Affairs, Estonia & Vice-Chair, ICPeMed

“Big data will become a key enabler for progress in many dimensions of healthcare. Together with other digitalization techniques it will transform healthcare professions. Exploiting the potential requires adaptation of curricula.

The five grand challenges of big data are first making data accessible for research and therapy, second understanding the chances and risks of big data and acquiring the necessary skills, third the

collaboration across multidisciplinary teams, fourth lowering the entry barriers for true ethical reflections beyond institutional bureaucracy, and fifth communicating successfully to policy makers and the people, what is at stake when we not use big data.

Using big data carelessly is unethical, but not using big data is unethical, too!"

- **Reinhard Riedl**, Head of Transdisciplinary BFH Center Digital Society, Berne, Switzerland

"The sharing of data across borders is key for both rare diseases and personal medicines. If we have the ability to track health outcomes, we can take these learnings and confirm the knowledge we already have. Advancing personalized healthcare requires data sharing."

- **Vinciane Pirard**, Senior Director Public Affairs (Europe & International), SANOFI Genzyme

"We can learn from rare diseases as it demonstrates the possibility to work across borders. Electronic health records exist, but the problem is that this data isn't accessible or shared. Not only does data need to be digitalised and analysed, but we need to extend access to data at regional and national levels and even across borders. However, this requires the political will and it requires that we have data protection and legal aspects in place. It is also important that patients have access to their data and the ability to use it in their home country or in another Member State. Patients need to be part of the data management."

- **Terje Peetso**, Head of Sector eHealth & Ageing policy, DG CONNECT, European Commission

"It is extremely timely that this year's EHFG is giving so much attention to big data and research. However, we need to be aware that more data is not necessarily a good thing, as we should do better in using the data that already exists. In this regard, we can benefit from collaborating with all stakeholders as we are doing in the All.Can #initiative, to improve efficiency by using what we have."

- **Wendy Yared**, Director of Association of European Cancer Leagues