Cancer Care:
Ensuring that digitalisation benefits rare cancer patients…

Welcome & Opening Remarks…

Fedro Peccatori + Markus Wartenberg
RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates
February 10, 2022
Healthcare & (Rare) Cancer: Some general trends and challenges (excerpt)…

- Future: Cancer will increase!
- Poorly used: Prevention & Early Detection
- Age of “Personalized Oncology” >>> Testing! Data!
- We need: Faster - better – access to affordable therapies!
- Dramatic differences between hc-systems
- Time and cost pressure in our hc-systems – on clinics and employees
- Still poor patient (customer) involvement (e.g. in politics, research)
- In several countries - poor health literacy (also digital)
- Lagging digital infrastructure, investments
- Many unused "data treasures"
- Research = hurdles, bureaucracy e.g. data protection
- Special situation of patients with rare cancers

02/03/2022
Future: An important key for solving the challenges but also for making progress...
Healthcare & (Rare) Cancer: Digitalisation will be a very important key…

And digitalisation is already going on in our healthcare systems – (…not just since Covid-19...)
**Digitalisation** has already and will continue to shape our societies...

- **e.g. Trends & Drivers**
  - Digitalisation
  - Globalisation
  - Demographics
  - Climate Change

- **e.g. Areas of Life**
  - Work and Income
  - Migration and Integration
  - Mobility and Urbanization
  - Age and Health

*Quelle: Prognos & Capgemini 2018*
Digitalisation has already and will continue to shape our societies...

The World's Most Valuable Brands 2020
Brand value of the most valuable brands in 2020 (in million USD)

<table>
<thead>
<tr>
<th>Brand</th>
<th>Value</th>
</tr>
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<tbody>
<tr>
<td>Amazon</td>
<td>415,855</td>
</tr>
<tr>
<td>Apple</td>
<td>352,206</td>
</tr>
<tr>
<td>Microsoft</td>
<td>326,544</td>
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<td>Google</td>
<td>323,601</td>
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<tr>
<td>VISA</td>
<td>186,809</td>
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<tr>
<td>Alibaba.com</td>
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<tr>
<td>Tencent</td>
<td>150,978</td>
</tr>
<tr>
<td>Facebook</td>
<td>147,190</td>
</tr>
</tbody>
</table>

Source: WPP/Kantar

Think about how naturally we use it today:

- Push-button phone vs. Smartphone
- Encyclopaedia vs. Wikipedia
- To Go Shopping vs. Amazon
- Video Library vs. Netflix/Prime
- Travel Agency vs. Expedia or Booking
- Bank Branch vs. Finance App
- Taxi vs. Uber

It will be the same in healthcare. Tools that seem unusual to us today will soon become standard...
Digitalisation has already and will continue to shape our societies...

<table>
<thead>
<tr>
<th>In BN $</th>
<th>Wireless Health</th>
<th>Mobile Health</th>
<th>Telehealth</th>
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<tbody>
<tr>
<td>2020</td>
<td>110</td>
<td>46</td>
<td>26</td>
</tr>
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<td>2019</td>
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</tr>
<tr>
<td>2015</td>
<td>39</td>
<td>8</td>
<td>12</td>
</tr>
</tbody>
</table>

![Global Market Insights Digital Health Market](chart.jpg)
What can we achieve with this session today?

Impossible to explain the whole (world) topic of Digital Heath in just 90 Min.!
(This can/should be done in other formats/trainings for patient advocates.)

- Today we would like to give Patient Advocates “food for thoughts“ that – DIGITAL HEALTH
  * is an incredibly important field to address,
  * also affects the world of rare cancers (challenges and chances),
  * is a topic where all stakeholders need to work closely together and
  * that Patient Reps. need to be involved here – need to advocate here.

- In the future: If we don’t want digitalisation to happen above us – without us or our health data are "misused" by Apple, Google, Facebook and Co.!!! We need to act in our HCS…

So: Let’s hear today perspectives from different stakeholders (physicians, nurses, hospitals, patients) and let’s exchange experiences and opinions together…
Perspectives of key stakeholders on the challenges and the opportunities…

Telepathology and telemedicine: Giancarlo Pruneri, University of Milan
What has changed during COVID-19 for rare cancer patients?

The hospital’s perspective: Jean-Yves Blay, ERN EURACAN, Rare Adult Solid Cancers
The physician’s perspective: Virginia Ferraresi, Istituto Regina Elena
The nurse’s perspective: Helena Ullgren, European Oncology Nursing Society (EONS)
The patient’s perspective: Markus Wartenberg, Sarcoma Patients EuroNet (SPAEN)

Discussion: Experiences, Opinions, Conclusions
Cancer Care: Ensuring that digitalisation benefits rare cancer patients…

The Patient (-Advocates) Perspective…

Markus Wartenberg
RCE-ESMO-ESO Training Course for Rare Cancer Patient Advocates
February 10, 2022
Disclosures Markus Wartenberg

The industry has no direct or indirect influence on my work. (No personal or business relationships with industry!)

Markus Wartenberg
SPAEN Sarcoma Patients EuroNet
German Sarcoma Foundation
Nat. NCT Patient Research Council
Digitalisation is changing healthcare systems and the role of patients

**YESTERDAY**

Attitude: My doctor knows best – what is good for me.

Knowledge – dominated by doctors
Very limited: Access to patient-understandable information

Patients choose their doctor based on distance, diplomas, word of mouth, etc.

Nearly no or limited ways
- to compare doctor’s services
- to find specialists for Rare Cancers (RC)
- to get in contact with pat. groups

Access to clinical trials – often just by chance

**TODAY**

The patient = customer (or should be) > Shared Decision Making

Online: Lots of information available
Challenges: To find the right, true qualified, understandable information

Upcoming e.g.: online pharmacies and very fast >>> digital health services/tools
(What happens with my data?)

RC: Much easier to find info, patient orgs., experts, studies – even across borders

Patient satisfaction and ratings are shared publicly – Social Media...

Patients may know options before meeting the doctor...

**TOMORROW**

Healthcare is becoming a market place and a data place
- Democratisation of medicine
- Digitalisation of medicine

Physician-Patient-Relationships = real and virtual –
(Patients are receiving more care at home!)

Clinics/doctors: Success rates, quality and satisfaction will become public

Big Data = Big Business!
data treasures, data collection, real life data
Who is owning the data?

More patient-centric R&D > Patient Involvement in Cancer Research!
Digitalisation is bringing support, care, research and other solutions to our homes.
Digitalisation will bring solutions (improvements) also for our Rare Cancer Community (RC)

Challenges in RC (excerpt):

- Epidemiology, numbers, data are insufficient
- Some types/subtypes are not curable (survival rates – rare vs. common cancers)
  - Often: Little options to take therapeutic decisions
- Late and incorrect diagnosis
- Lack of clinical expertise (expert centers)
- Lack of research interest and development of new therapies
- Difficulties in carrying out clinical trials in very small patient populations
- Innovative clinical trial approaches
- Financial support for research
- Pharma: investments in small markets > cost-effective drugs
- etc.

Solutions for RC - through digitalisation (excerpt):

- finding expertise (centers) faster, better (but also: rate/evaluate them)
- global knowledge (not only in English – digital translations!)
- contact to PAGs and to mutations-spec.-groups (incl. improvement for PAGs)
- A.I. > faster/better diagnoses and therapy suggestions...
- spec. types/subtypes: bringing data, experiences and patients globally together
- through apps/portals/tools patients feel linked to a community, a center or a study
- relief of clinic staff from “stupid activities” - more time for patients and research
- targeted solutions or small studies can be offered to patients in registries
- access to studies - national / across borders (virtual/digital studies)
- collecting / analysing data, existing, clinical diagnostic, QoL, real word data
- connecting centers / experts to areas/countries – with less expertise
- innovative clinical trial approaches
- financial support for research
Some needs/considerations for the process of digitalisation…

**Not digitising around for the sake of digitisation…**
Digital health has always to benefit patients, societies and healthcare systems – not just companies/shareholder…

**Don’t just develop from theory and assumptions…**
Involve the target groups such as patients or employees – what they expect from
* the digitalisation in general and
* from specific projects

**Urgent: Significantly more investments in digitalisation…**
We don’t want so see our health data in the near future only at the eCompanies (US, Asia) or at “Big Pharma”…

**A must: “Patient Involvement in Digital Health” (incl. education)…**
- Healthcare Systems
- HC-Provider
- Insurer, Payer
- Pharma-Companies
- IT-/eCompanies (Start Ups)
- etc.

**Leaving Silos: Collaboration, transparency, networking are crucial – nationally and across borders…**
RC: Pilot projects to learn from and to share. (Limited resources!) Don't try to reinvent the wheel…

**Data regulations, harmonisation and elimination of hurdles / bureaucracy are important…**
- e.g. data protection in research
Example 1: Training/Education of Patient Advocates

- In 2021 = conceptual redesign of the National Center for Tumor Diseases (NCT)
- Essential and unique - here: Patient Involvement In Cancer Research Concept: “Patients as Research Partners”
- Went life in the summer 2021 (with a pilot): PEAK = National Patient-Expert-Academy

Training/Education in 4 areas:

- Area 1: Patients as Research Partners
- Area 2: Founding, Managing and Leading Patient-Structures
- Area 3: Evidence Based Patient Advocacy
- Area 4: Patient Involvement in Digital Health
Example 2: Vision “Qualitative Sarcoma Network”

Nat. Network: Combining treatment, research, data
“Sarcoma Treatment Digital Ecosystem”
All sarcoma patients have early access to a
qualified (…and digitalised…) "network" >
- with access to qualified (real) sarcoma centres,
- modern and personalised sarcoma therapy
  * based on pathological and molecular diagnostics = data
  * to offer them partly even innovative therapies
- and collaborative research (…trial, data, tissue…)

Research (…as a natural part of care…) is offered directly (automatically) to patients and we do not longer see patients looking (desperately) for research options (solutions)…