



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

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...

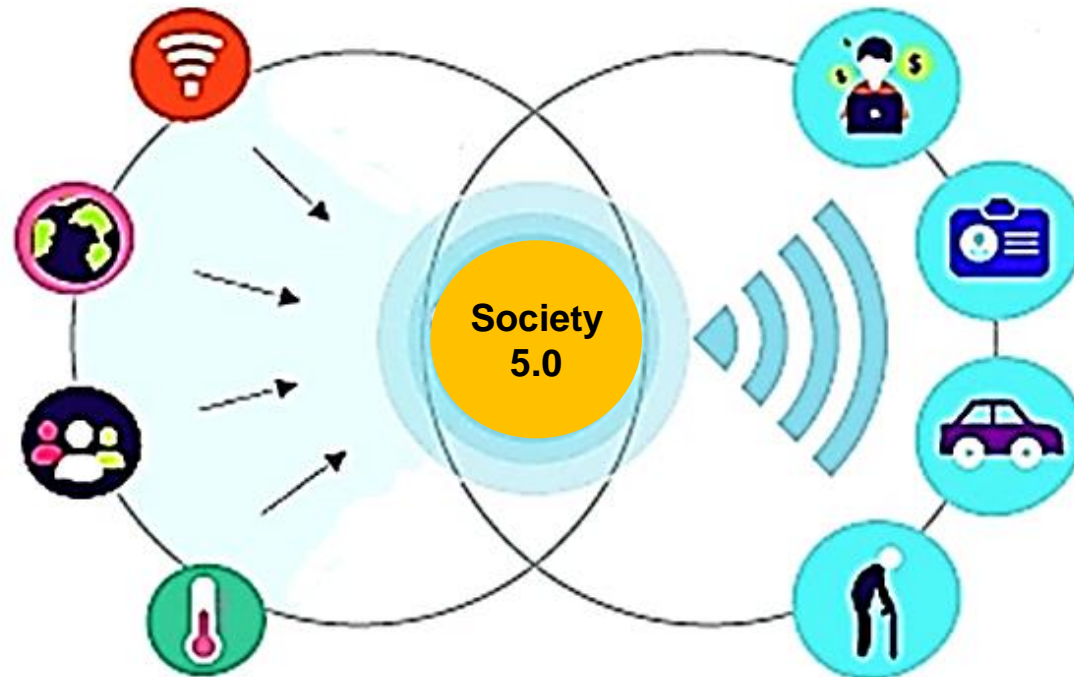
e.g. Trends & Drivers

Digitalisation

Globalisation

Demographics

Climate Change



e.g. Areas of Life

Work and Income

Migration and Integration

Mobility and Urbanization

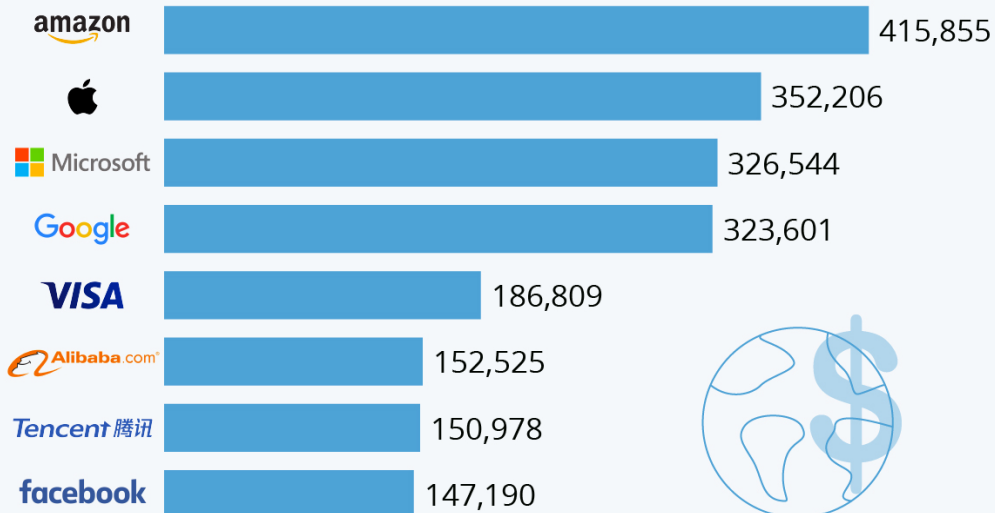
Age and Health

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)



Source: WPP/Kantar

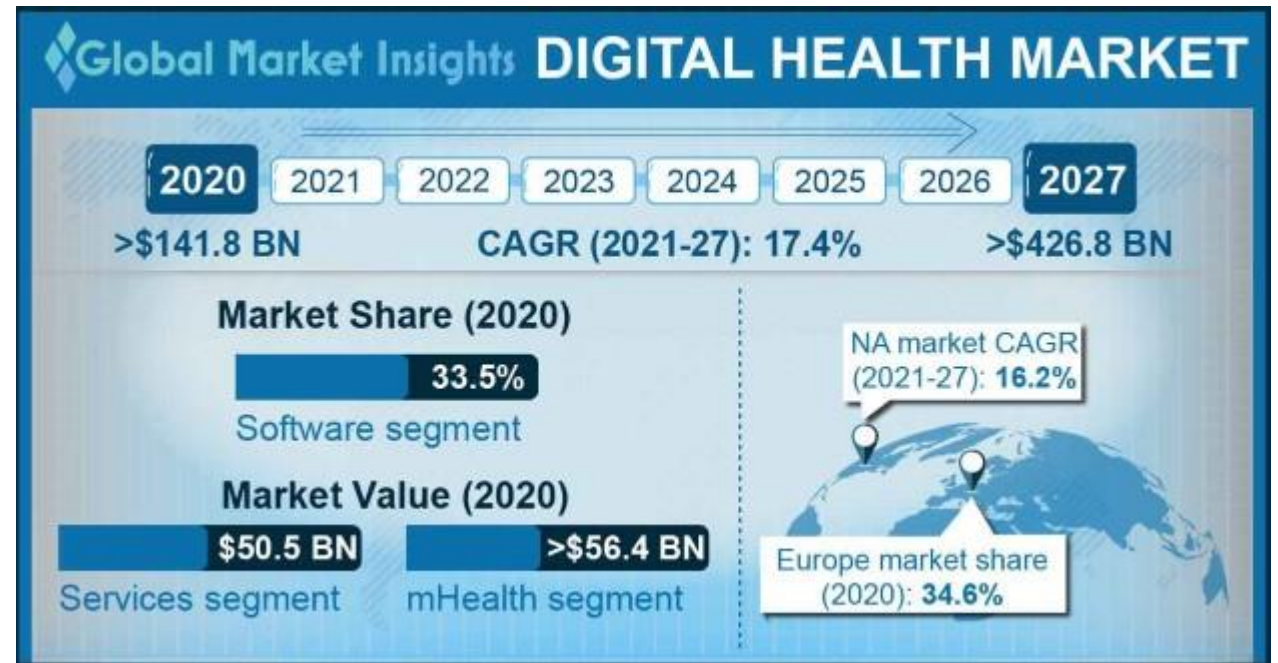
Think about how naturally we use it today:

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...

In BN \$	Wireless Health ↕	Mobile Health ↕	Telehealth ↕
2020	110	46	26
2019	89	37	22
2018	73	28	19
2017	59	21	17
2016	48	14	14
2015	39	8	12



What can we achieve with this session today?

Impossible to explain the whole (world) topic of Digital Health 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

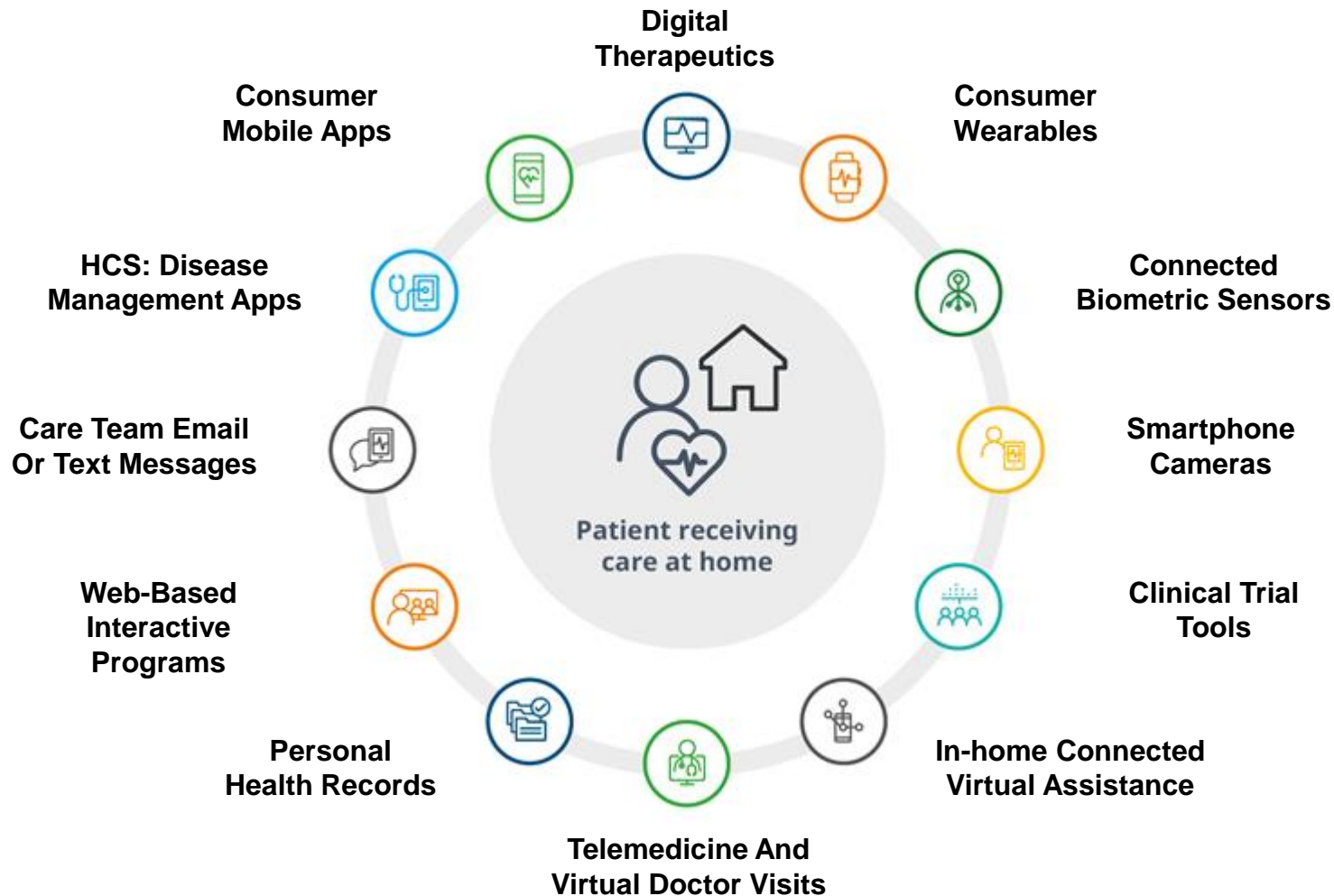
Physician-Patient-Relationships = real and virtual – (Patients are receiving more care at home!)

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

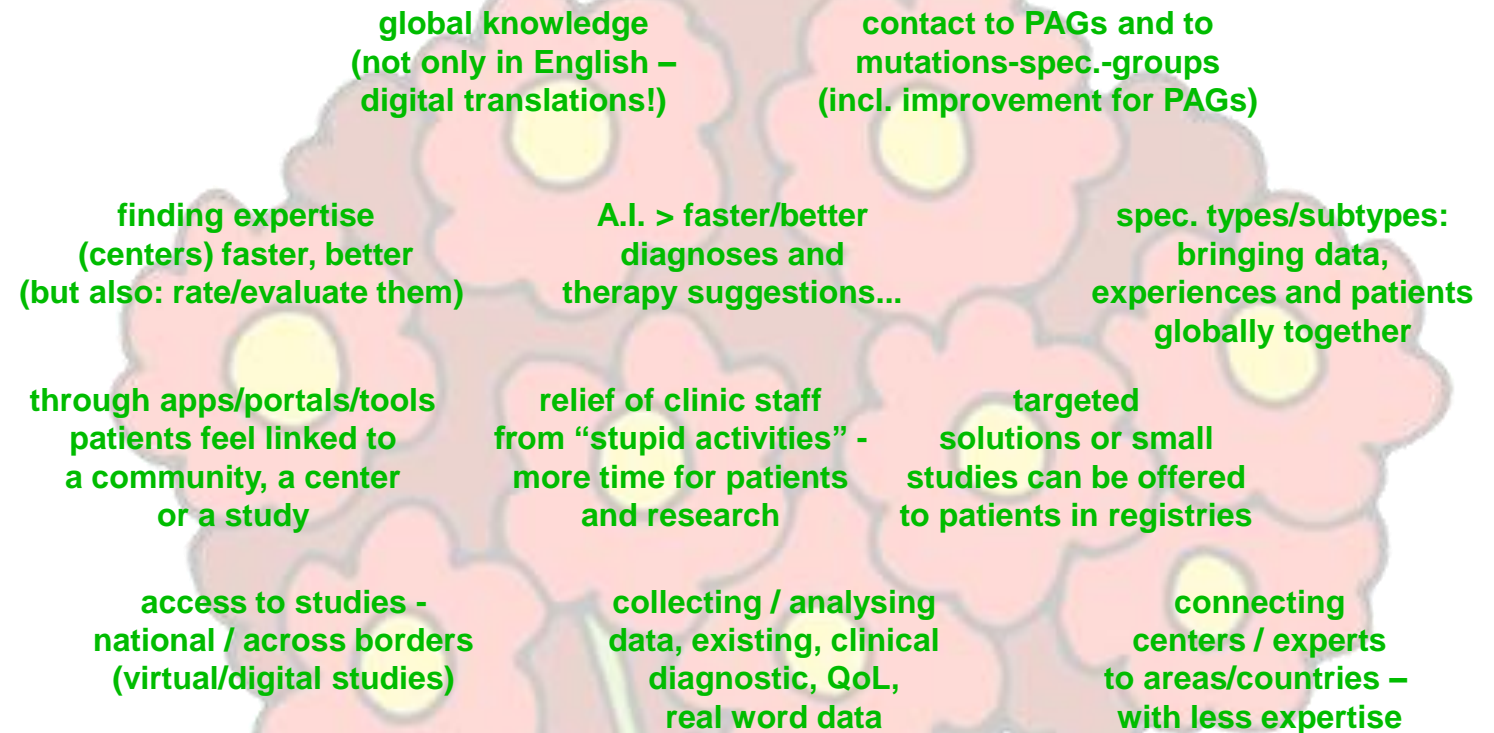


Digitalisation will bring solutions (improvements) also for our Rare Cancer Community (RC)

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):



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...

A must: “Patient Involvement in Digital Health” (incl. education)...

- Healthcare Systems
- HC-Provider
- Insurer, Payer
- Pharma-Companies
- IT-/eCompanies (Start Ups)
- etc.

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

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...

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”...

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 live 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
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)...

