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How might ehealth and digital technologies impact on palliative care practice and research?

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on behalf of the European Association for Palliative Care

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Transilvania University of Brasov
Faculty of Medicine

Hospice Casa Speranței
Making every moment count

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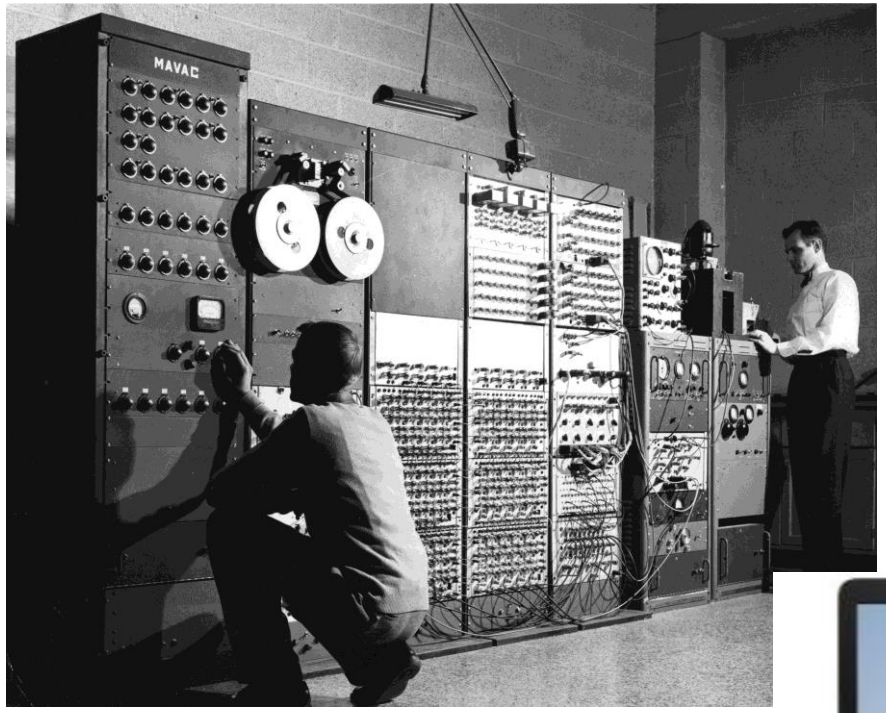
Information and communication technology



Room size computer 1960’s

NASA Control Room – Moon landing 1960’s

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Overview

- What are ehealth and digital health technologies?
- How might these digital technologies impact on palliative care practice?
- How might these digital technologies impact on palliative care research?
- Achieving a balanced way forward

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World Health Organisation Definition of eHealth

eHealth is the use of **information and communication technologies** (ICT) for health. It is recognised as one of the most rapidly growing areas in health today. The Fifty-eighth World Health Assembly in May 2005, adopted Resolution WHA58.28 establishing an eHealth strategy for WHO.

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European Commission Policy on eHealth

- Digital health and care refers to **tools and services** that use information and communication technologies (ICTs) to improve prevention, diagnosis, treatment, monitoring and management of health-related issues and to monitor and manage lifestyle-habits that impact health. Digital health and care is innovative and can improve access to care and the quality of that care, as well as to increase the overall efficiency of the health sector.
- "**A Europe fit for the digital age**" is one of the six political priorities of the Commission 2019-2024.

European Commission

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Digital technologies include....

- Electronic health records
- Telemedicine
- Smartphone apps
- Sensors and wearable devices (for diagnosis and monitoring)
- Speech recognition and natural language processing
- Virtual and augmented reality
- Artificial intelligence
- Robotics

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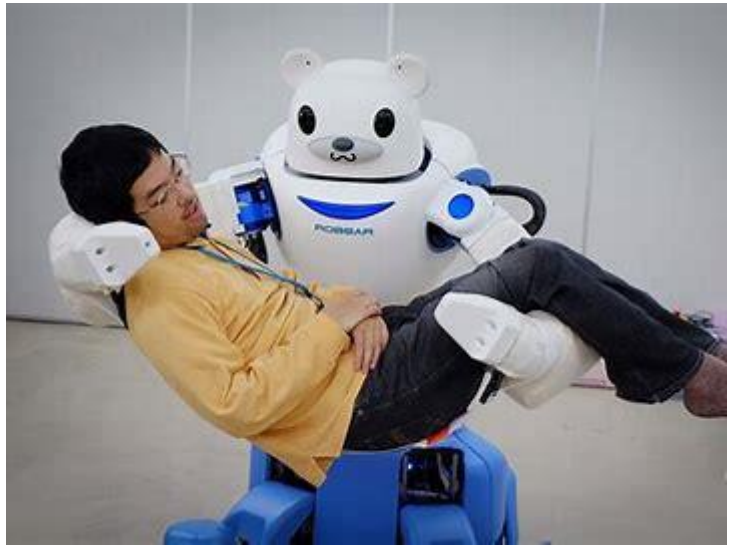
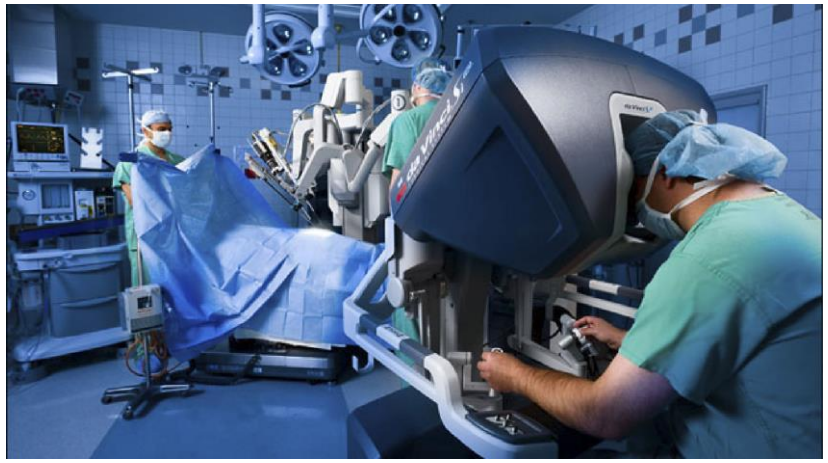
How many of these devices are already part of your life and work environment?





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Implications of digital health for palliative care

Principles of palliative care include:

- Establishing compassionate personal relationships with patients and families
- Respect for personal values and goals
- Empathetic listening and communication
- Enhancing dignity and patient-centredness
- Therapeutic touch
- Psychological, social and spiritual support

Gamondi C, Larkin P and Payne S. Core competencies in palliative care: an EAPC white paper on palliative care education – part 1. Eur J Palliat Care 2013; 20(2): 86–91

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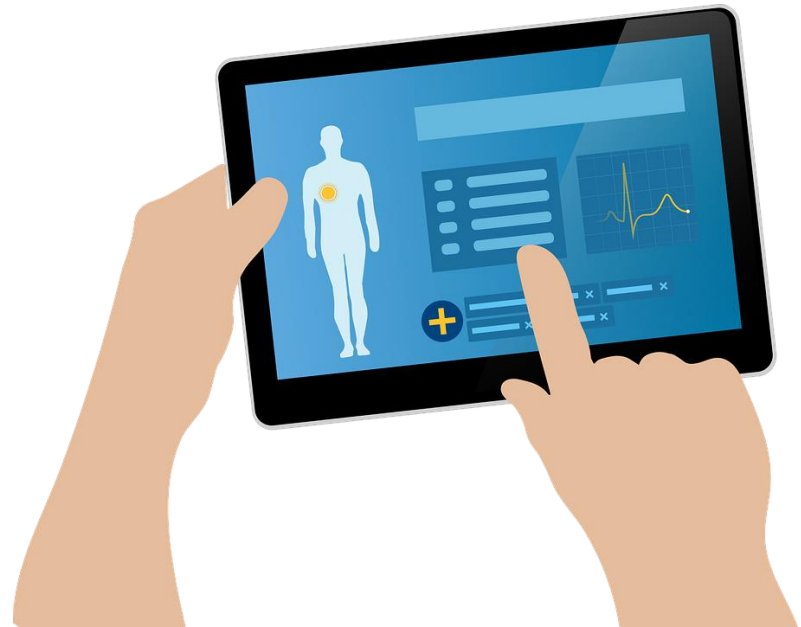
Electronic medical records

- Advantage for rapid sharing of information across teams and organisations
- Only need to ask medical history once
- Can share information with patients if they have access

BUT

- Accuracy, security and privacy of data
- Availability of access to devices
- Need to update systems



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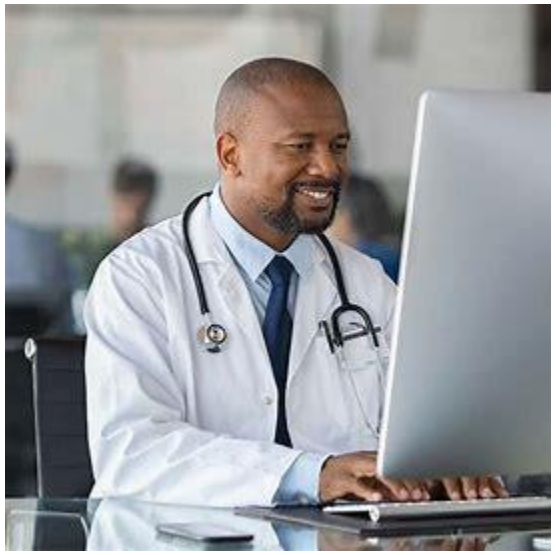
Shift of focus from patient to computer screen?

Study of junior hospital doctors in USA showed that in each shift

50% time spent on electronic record



10% time interacting with patients

Mamykina L, Vawdrey DK and Hripcsak G. How do residents spend their shift time? A time and motion study with a particular focus on the use of computers. Acad Med 2016; 91(6): 827–832.

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The doctor will see you now...

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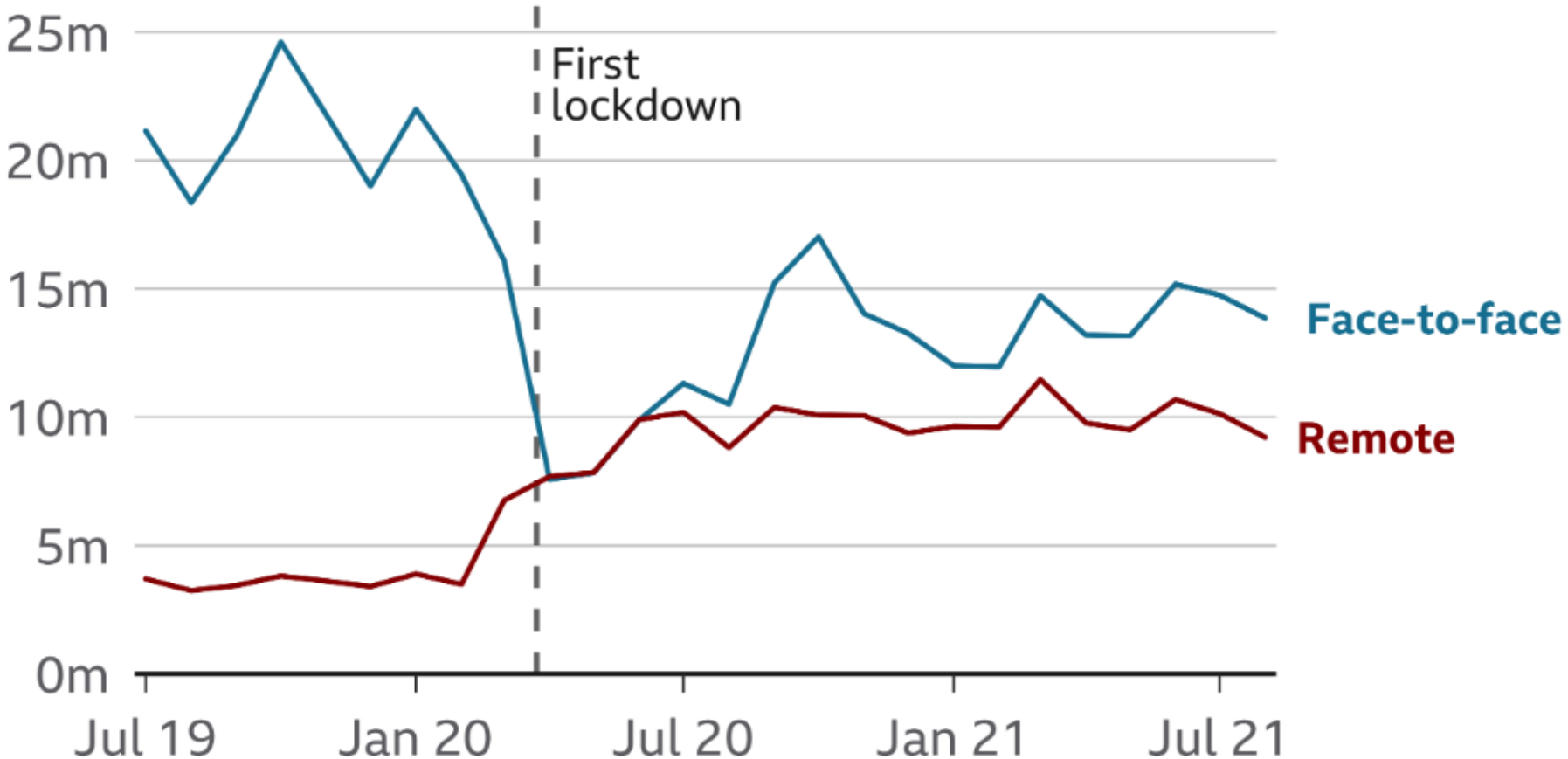
How GP appointment types have changed

Number of face-to-face and remote appointments as recorded by GP practices in England each month



"Face-to-face" includes home visits, "remote" is made up of telephone and video/online appointments. Up to 5% of appointments are recorded as "unknown".

Source: NHS Digital

BBC

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Increasing use of telemedicine

- Direct access to specialist palliative care providers
- Less travel time to clinic
- Helpful for those living in remote and rural areas

BUT

- May be difficult to deliver psychological support
- May disadvantage older people, those with less digital access and literacy
- Those who do not speak the national language

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Investigating the use of smartphone apps

MyPal: Fostering Palliative Care of Adults and Children with Cancer through Advanced Patient Reported Outcome Systems

Start date: 1.1.2019. *Duration*: 4 years

- https://mypal-project.eu/

European Commission | Horizon 2020 European Union funding for Research & Innovation

@H2020MyPal

@MyPalProject

www.linkedin.com/company/mypal-h2020

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Key aspects of the MyPal study

- Aims to foster general palliative care for adult and children with haematological cancers
- MyPal uses technology to support patient care, and allow them, their family caregivers and health care professionals to interact and share information through a mobile health app.
- Uses electronic patient reported outcome measures (ePROs) to enable self-reporting of symptoms
- Uses wearable sensors to record mobility and sleep

MyPal ADULT study protocol: a randomised clinical trial of the MyPal ePRO-based early palliative care system in adult patients with haematological malignancies | BMJ Open

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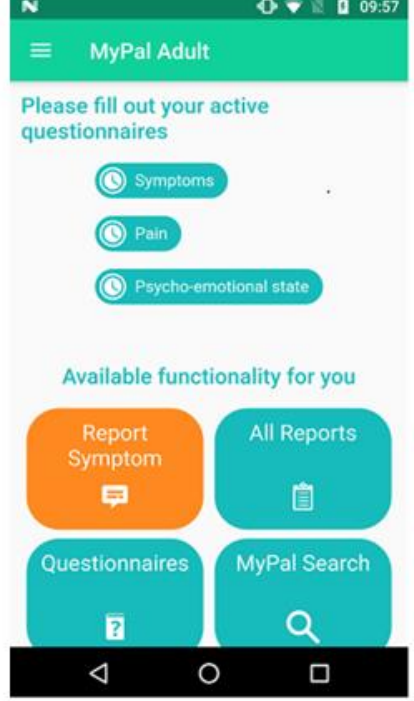
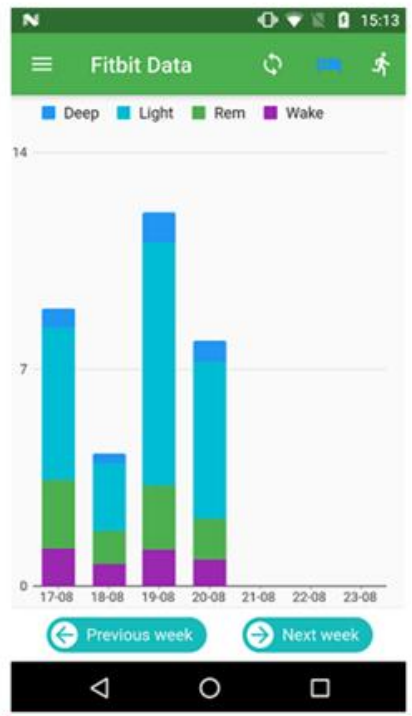
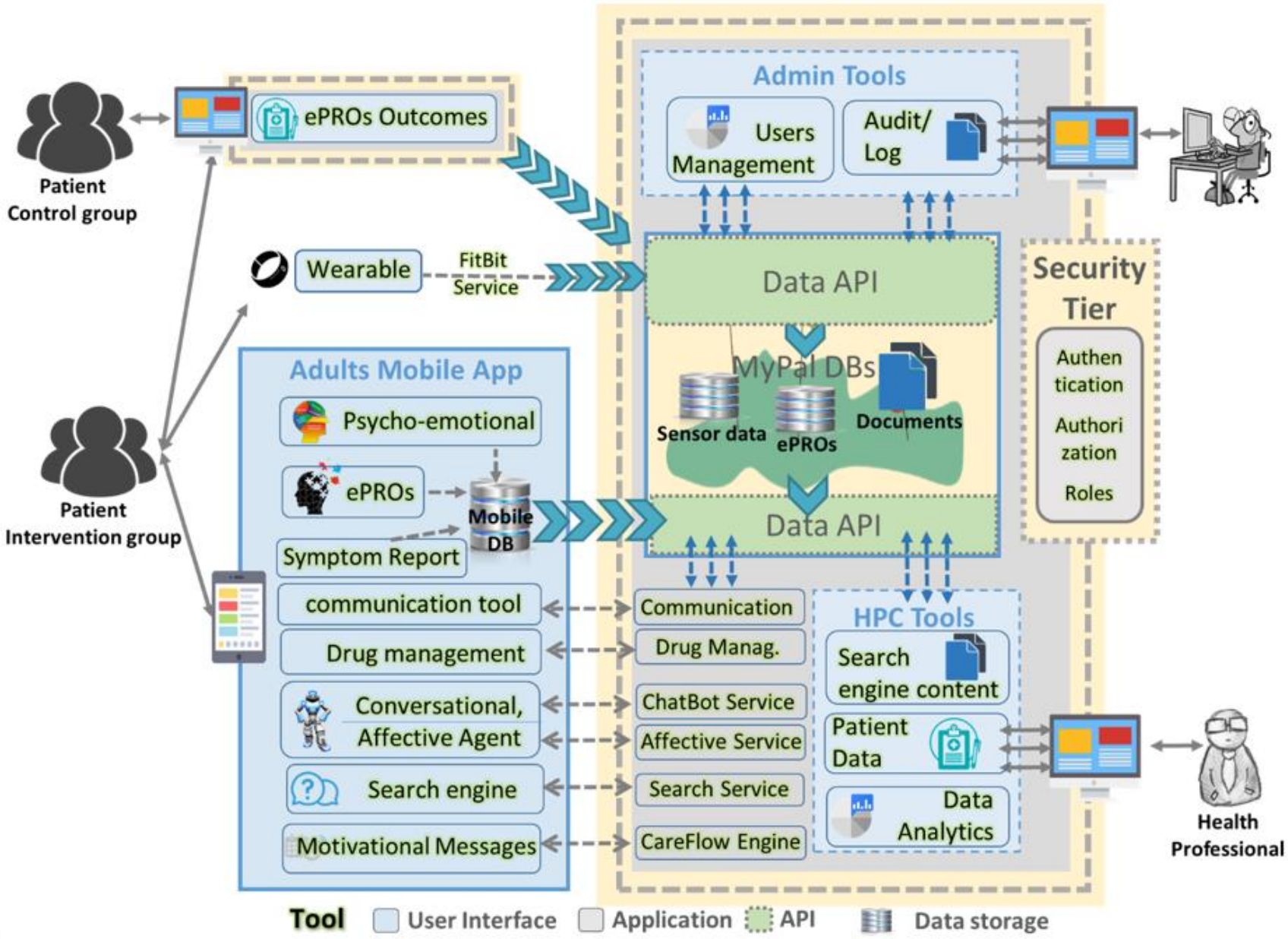
Example of MyPal app for Adults






Patient
Control group
ePROs Outcomes
Admin Tools
Users Management
Audit/ Log
Wearable
FitBit Service
Data API
Security Tier
Authen tication
Authori zation
Roles
MyPal DBs
Sensor data
ePROs
Documents
Data API
Adults Mobile App
Psycho-emotional
ePROs
Mobile DB
Symptom Report
Patient
Intervention group
communication tool
Drug management
Conversational, Affective Agent
Search engine
Motivational Messages
Communication
Drug Manag.
ChatBot Service
Affective Service
Search Service
CareFlow Engine
HPC Tools
Search engine content
Patient Data
Data Analytics
Health Professional
Tool
User Interface
Application
API
Data storage

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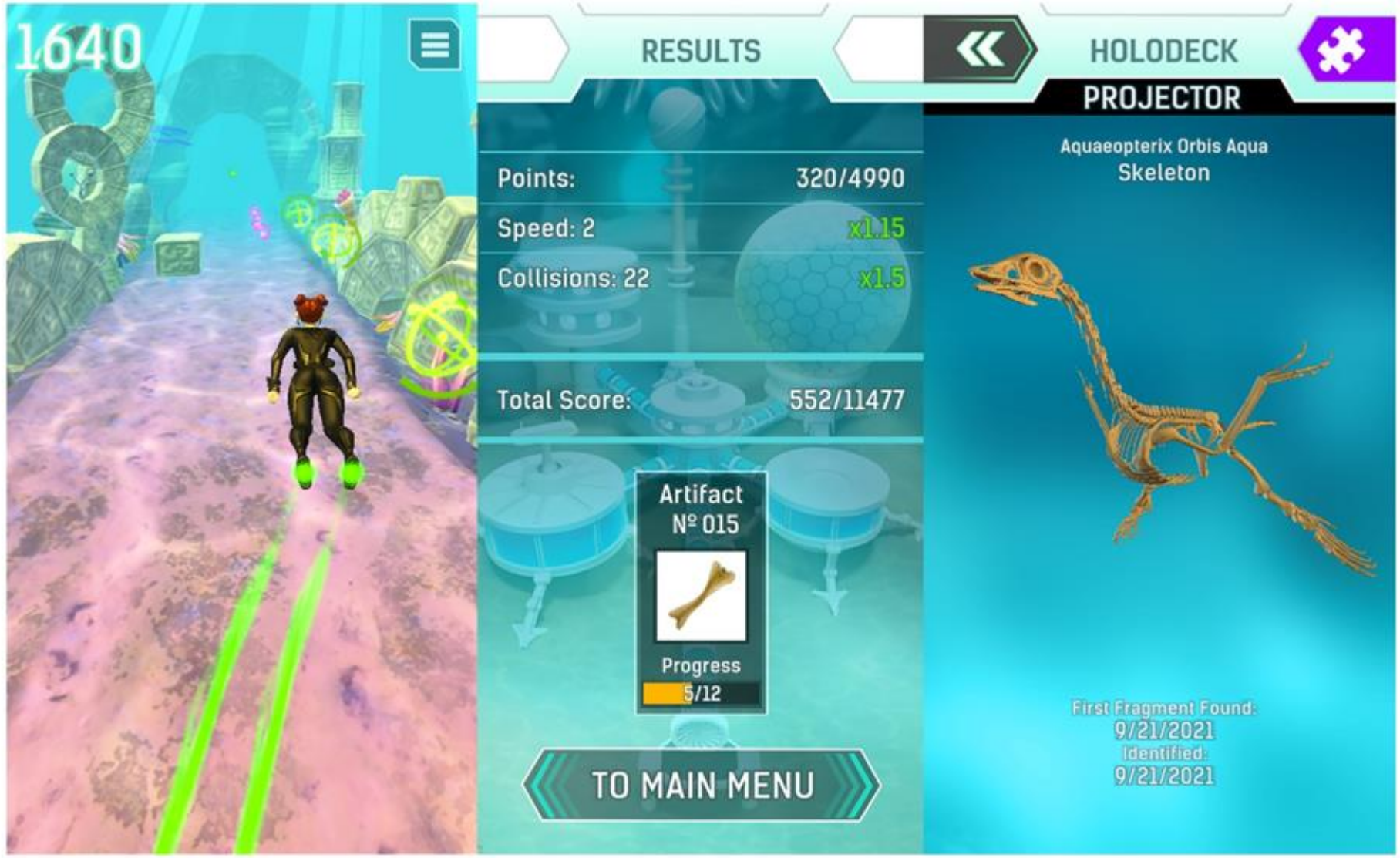
Gamification of MyPal Child app


1640
RESULTS
HOLODECK
PROJECTOR
Points: 320/4990
Speed: 2 x1.15
Collisions: 22 x1.5
Total Score: 552/11477
Artifact
№ 015
Progress
5/12
TO MAIN MENU
Aquaeopterix Orbis Aqua
Skeleton
First Fragment Found:
9/21/2021
Identified:
9/21/2021

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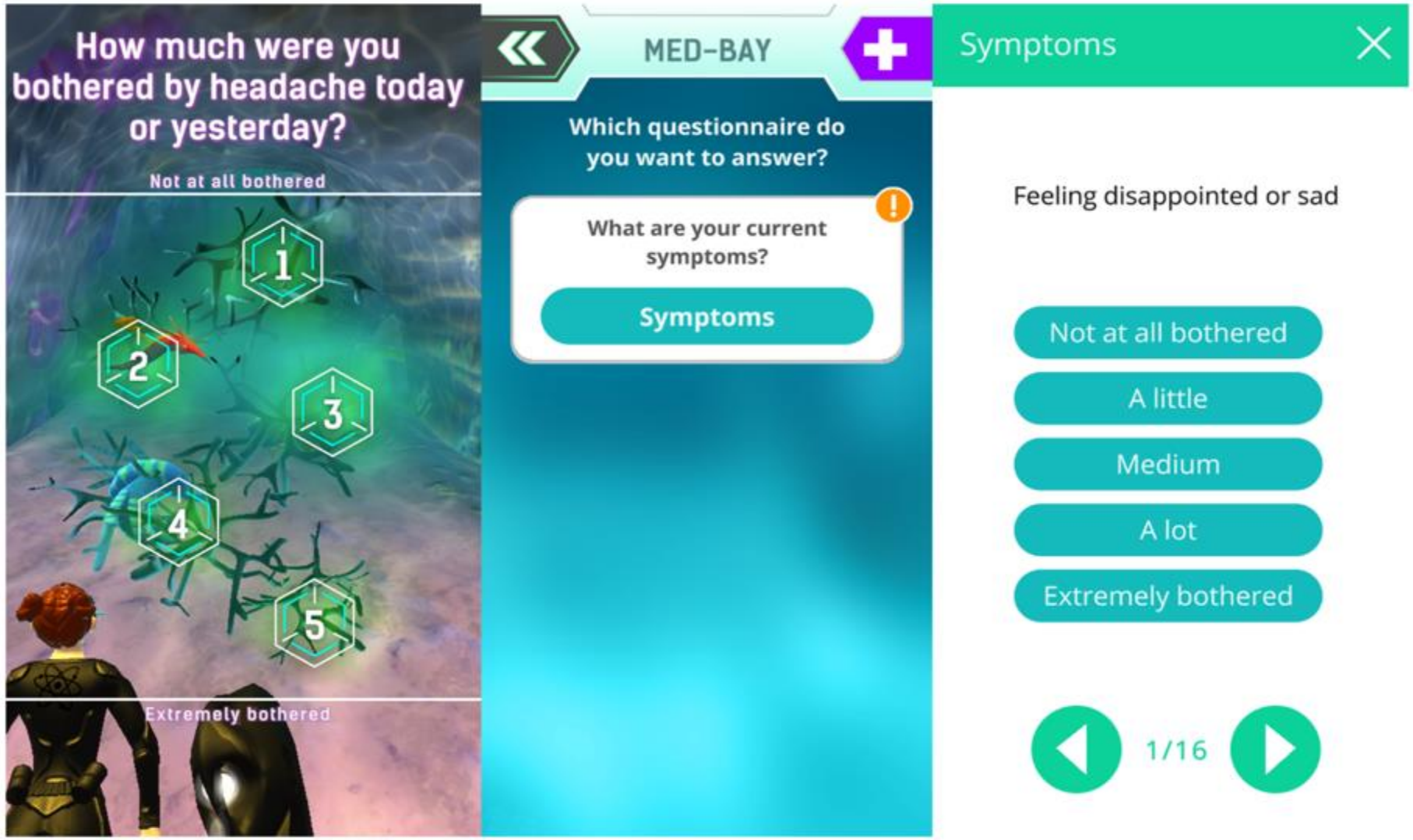

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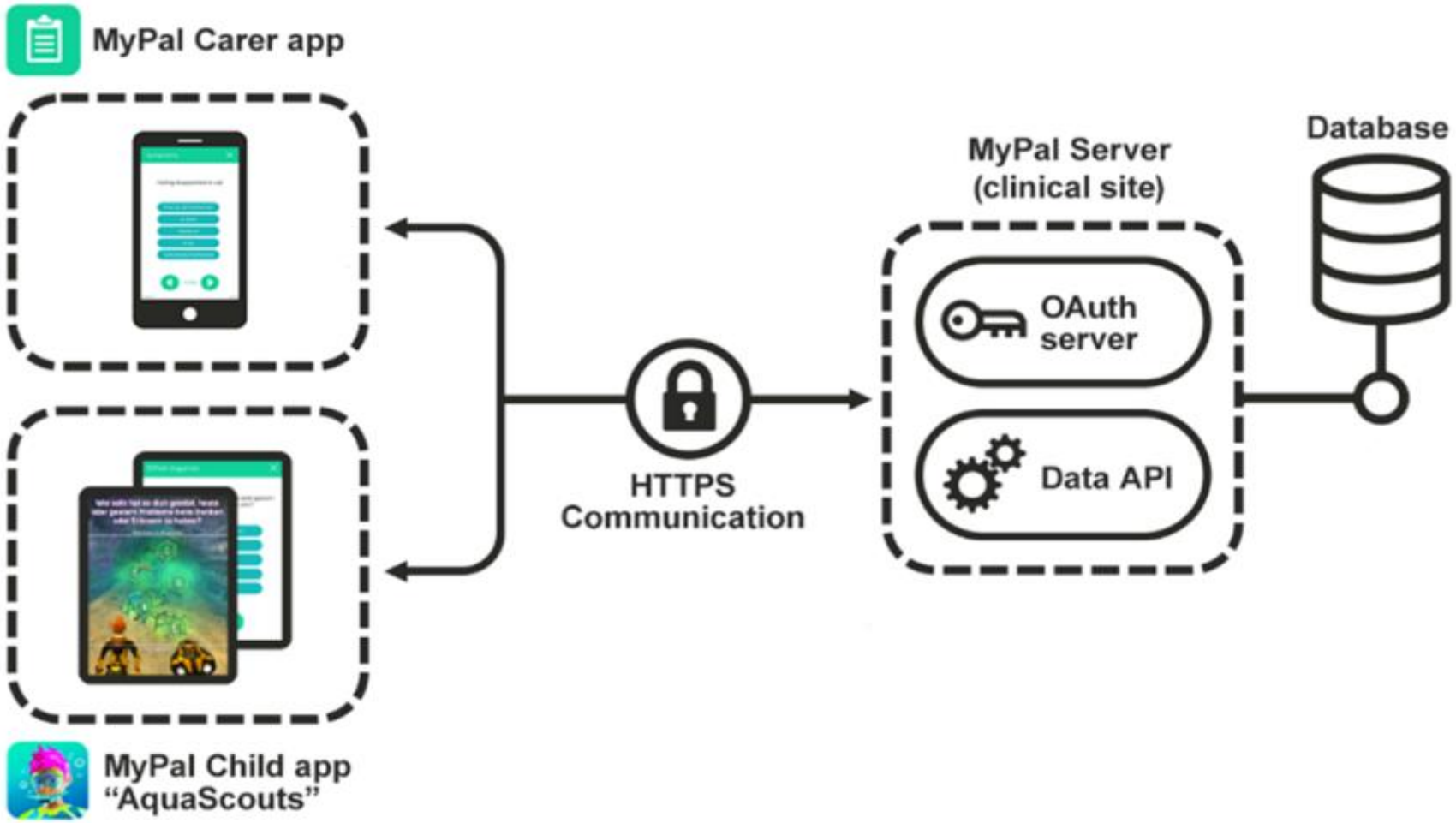

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Project summary and update

MyPal Adult (randomised control trial)

Objective: To determine whether the MyPal-Adult intervention can lead to improved QoL compared to standard care as evidenced by statistically significant higher scores in EORTC QLQ-C30 General Questionnaire and EQ-5D. **Population:** 300 adult patients diagnosed with haematological cancers (CLL/SLL or MDS) recruited from 5 hospitals in Greece, Italy, Czech Republic, and Sweden.

n=150 access to MyPal app with ePROs + Fitbit

n=150 usual care

MyPal Child observational prospective feasibility study (MyPal4kids)

Objective: To determine whether the MyPal-Child intervention is feasible and acceptable and to evaluate newly designed digital health platform to contribute to the evidence base of clinical ePRO use in paediatric oncology and palliative care process. **Population**: 100 child patients (6-17 years) diagnosed with haematological/solid cancers and their parents recruited from 3 hospitals in the Czech Republic and Germany.

MyPal app for children (serious game)

MyPal app for parents

HCPs access to ePROs

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Advantages and challenges of using smartphone apps

- Patients can be proactively engaged in their own care
- Better communication with health care team

But

- Concerns about privacy and confidentiality
- May discriminate against marginalised groups (older people, less IT literacy, less access to devices + internet)
- Focus may be restricted to reported symptoms, less holistic care, less social and spiritual support

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Advantages and challenges of using wearable devices and sensors

- Easier to monitor patient's condition
- Less staffing required
- Real-time data available

But

- Focus on what can be measured and 'seen'
- Can be perceived as invasive of privacy
- Risk of having more information about patient's physiological functions but less knowledge about them as human beings

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Increasing use of robotics to provide care

- May enable patients to remain at home
- Assist in manual handling tasks like lifting
- Less staff required

But

- Depersonalising?
- Limited relationships

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Implications of digital technologies for palliative care research

Priorities identified in a Delphi study (Nwosu et al 2022)

- Telehealth
- Exploring Artificial Intelligence
- Big data
- Mobile devices and wearables
- Virtual Reality technology
- The Smart home
- Biotechnology
- Digital legacy

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Potential priorities for future research

- How acceptable are digital interfaces for different populations and users?
- How to make systems and devices compatible and secure across organisations?
- How to establish and maintain relationships across online media?
- What is the impact and expectations of 24/7 connectivity for health professionals, patients and families?

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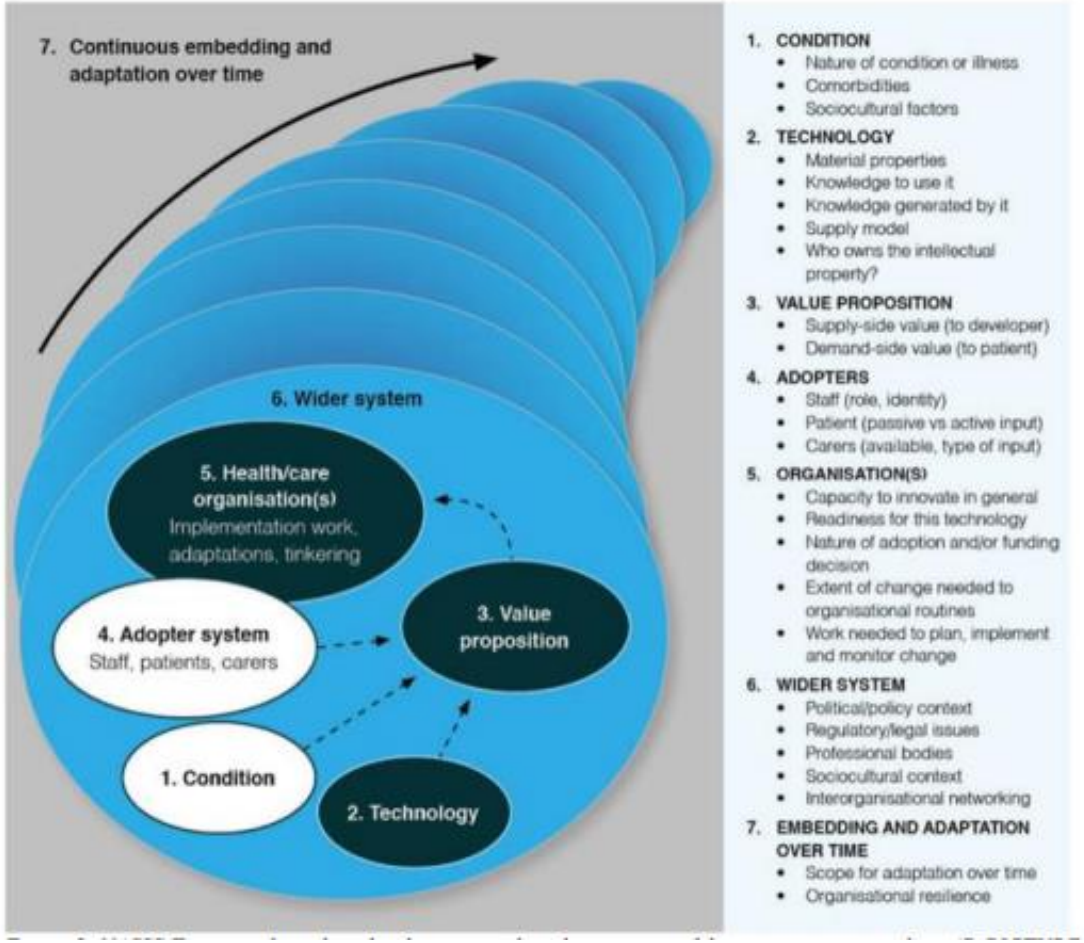
80% of data- and technology projects in healthcare fail to be implemented successfully after the lifetime of a study

(Greenhalgh, Abimbola; Stud Health Technol Inform. 2019 30;263:193-204.)

NASSS Framework

- Not **adopted**
- **Abandoned** by professionals
- Fails to **Scale** up
- No **spread** to others
- Not **sustainable**



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Reflections and the future

- Digital health technologies will be part of the future of palliative care
- Sensitive and compassionate communication is central to palliative care
- What is the acceptability of digital solutions?
- Access to 'real' care providers as patients become too weak, ill, distressed and confused to use communication devices.
- Recognising that 'being with' the patient and family are essential aspects of palliative care (Speakman L (2018) Challenges of 'being with' patients nearing at the end of life. *Nursing Times* [online]; 114: 4, 28-30)

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Thank you for your attention

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