Panel 3
Panel on Telemedicine and Healthcare
Theme: Data Analytics and Health Management
(patient records, remote medicine, personal data, self-care monitoring, elderly, caregivers, mental wellbeing, wearable, etc.)

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**Elderly’s Health Data Management in Digital Environments**

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- Health data management
- Digital technologies
- Elderly people
- Health Care System
- Quality of care

→ Elder people have difficulties to manage their digital health data
→ Digital self-care monitoring should be framed by the Health Care System to provide the quality of care
→ Co-production of digital health innovation
Elderly’s Health Data Management in Digital Environments

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Introduction

Digital health data and information/literacy is sometimes hard to manage for elderly people, because of their difficulty to handle digital devices (Vigouroux-Zugasti, 2018; Caradec, 2012; Guérin, 2011)

It is all the most a sensitive issue for them that aging leads to the increase and/or the aggravation of health pathologies (Caradec, 2011; Adam & Herzlich, 2013; Vigouroux-Zugasti, 2017)

On the one hand, elderly people have to face new difficulties in the management of their health and, on the other hand, they have to « get » digital (Granjon, 2012), especially since the beginning of the pandemic COVID-19, that led the Public Health Authorities to promote the use of telemedicine.

In that context, how could the Health Care System help elderly people manage their digital health information and, doing so, guarantee the quality of care?
Digital health technologies (DHT) and elderly people: a difficult path to self-care

Many studies highlight that current DHT do not correspond to the real needs and digital skills of elderly people (Morozov, 2014; Strauch, 2014; Rivière & Brugière, 2012; Vigouroux-Zugasti, 2017, etc.). This is particularly the case in France.

According to these studies, the main problems are due to a partial consideration of their digital and health literacies, to some difficulty to consider the heterogeneity of this population (in terms of age, social environment, health status, digital literacy, interests for digital technologies, access to equipment, etc.) or even due to some solutionist and mercantile approaches of digital health technologies.

As a result, digital health technologies have some difficulties to be adopted by all the categories of elderly people, especially those who could benefit the most from it – i.e. people with chronic disease and/or people over 75 years old (INSEE, 2019).
The COVID-19 : an opportunity to impulse changes in elderly’ health data management

However, the pandemic of the COVID-19 tends to overturn the current uses of digital data : in order to protect themselves from the virus, the most fragile patients (chronic diseases + aging people) are encouraged to develop their digital literacy, applied to self-care and to the relationship with medical professionals (telemedicine, teleconsulting, health assessment with digital devices, etc.).

This context involve some social/technical innovations to overcome digital divides (Granjon, 2012), i.e. necessary breaks with previous practices, which become inadequate to the new public health needs (Lallemand, 2001) :

• Technical (first degree of divide) : support the accessibility to digital devices, especially for middle and low classes

• Social (second degree of divide) : support the development of digital skills and literacy among fragile populations, especially for the population who missed the digital transition (Vigouroux-Zugasti, 2017)
Methodology: qualitative surveys...

... on elderly digital users/patients

Goals:
• investigate uses of health data management
• highlight attitudes of trust/distrust towards health care system
• identify elderly’s interests for the development of digital health technologies

40 semi-directive interviews of elderly people over 60 years old (Jan. – April 2019)

Seek for the variety of criteria, based on national population distribution data, to have a representative sample: age, gender, place of living, social class, digital equipment, living standards

The analytical framework is based on a constructivist and comprehensive interpretation of the interviews, with a principle of thematization

... on multidisciplinary health organizations

Goals:
• understand professionals/patients relationships
• identify organizational data management strategies
• highlight opportunities for an active collaboration in elderly patients’ digital health management
• identify concerns about the development of DHT

Observations in situ in three French multidisciplinary health organizations (urban, semi-urban and rural)
9 specific focus groups with medical (3), paramedical (3) and administrative staff (3) + 3 focus groups with the whole staff of the organization
10 interviews with the Heads of the organizations (February – May 2020)

The whole staff was investigated in order to have a multidisciplinary overview on the investigated topics
Focused results: elderly users/patients

No use of connected health devices in the sample, regardless age, social class or digital equipment

95% of the sample do not have connected health devices or app on the smartphone, in which: 86,9% because of a lack of technical skills, 76,4% because they do not understand the purpose, 8% for economical reasons despite the high interest for those tools.

“Big Brother syndrome”: high rate of mistrust in digital health data management

87,5% of the sample declare to feel worry about tracking, hacking and data collection / reselling, so they willingly limit their health data management on digital devices or apps. In this part of the sample, 91,5% confess they do not understand the data policy on the websites / digital devices / apps.

Correlation between people who feel uncomfortable with their health literacy skills and the lack of trust in Public Health system and authorities

67,5% highly endanger themselves with their health practices on the Internet: self-medication based on illegitimate sources (chats, blogs, alternative medication) + misuse of the information they find: they generalize it to all health contexts, they do not take into account the drug interactions and they avoid to consult their doctor in case of new symptom to favor self-medication instead.

The reasons they put forward are based on an critical vision and on common senses about Public Health – which is perceived as a corrupted system – and health professionals – who, according to the interviews, are inintelligible, focused on their economical outcomes and who are not interested in their patients concerns.
Focused results: elderly users/patients

Endangerment of health data: improper disclosures of data caused by the user himself/herself
Due to the lack of digital data management skills, elderly people tend to disclose their health records in unappropriated contexts or to unappropriated people when they look for information (chats, blogs, etc.) concerning their health or when they look for information for someone else.

Correlation between health information literacy skills and valuation of (digital) health data
67.5% of the sample admit they have some difficulty to sort their health data, because they feel uncomfortable with their meaning. They mainly created a Dossier Médical Partagé (national digital health data record) for administrative reasons, but more than 90% of them do not use it (lack of trust in digital devices (87.5%), difficulty to understand the data (77.5%) or to sort the health data on the digital record (72.5%))

The people with the highest rates of health literacy correspond to those who avoid self-health monitoring on the Internet
In case of problem, they consult their doctor and get highly involved in this relationship. It also seems that they have a negative image of the DHT (97.5%), which they consider to be useless or to be health gadgetry.

Strong demand for coaching and training in health data management
When people are asked about their digital health management skills, they admit (87.5%) they would be interested to benefit from a real training, “not for everyday use, but to understand the digital health transition”
Essential to give access to the right information, at the right time : selective transmissions of data

The main goal of the organizations are to smooth organization of data sharing and to limit the risks linked to the poor dissemination of data inside and outside the organization. Patients data policy, in all the organizations of the survey, is considered as a key resource for the whole management of the institution.

Informational lean management for no unnecessary information

The professionals do not have the same accreditation for data access, according to the needs of the patient, the activity or the specialty. This policy tends to avoid misunderstandings and avoid the dissemination of superfluous information, in order to improve the performance of the organization and the monitoring of patients. In doing so, the institution tends to develop a very low entropy, with 0 useless information.

Hierarchy in information management

The ethical processing of information are the starting point of the organizations’ data policies, i.e. a mechanism for the interpretation of data, in order to assign meaning to it and extracting value from it (Béranger, 2012). By analyzing it, the organization extracts value that allows the definition of use cases for handling data (censorship, global dissemination, limited dissemination, etc.).

Difficulty in getting patients to comply with medical treatment

According to the medical and paramedical staff, there is a strong demand from the patients for prescriptions or therapeutic treatments, which, paradoxically, seem to be only partially or not at all complied.
Focused results: health organizations

Growing interest for therapeutic education of patients
Public Health authorities try to promote patients’ self-monitoring by developing therapeutic education. The medical professionals are in charge of this education, thanks to specific workshops with patients, especially those with chronic diseases. But the investigated medical staff confess that the workshops are difficult to set up, because of the little time they can spend on it + schedule constraints + lack of patients’ lack of regularity.

Need for active inter-organisational collaboration for data management and quality of care
One of the main topics mentioned by the organizations staff is the extra-organizational cooperation and collaboration, especially concerning software compatibility for the management of data. They explain that they would prefer working with institution working with the same software, in order to smooth and to guarantee the care processes and the security of data protection.

Covid-19: difficult use of the current means of teleconsultation and rejection of the national health record
With the current pandemic, health organizations have made extensive use of teleconsultation. However, according the interviewed medical staff, this technologies needs to be greatly improved to be really useful. The current software’s infrastructure is too heavy to be in adequacy with the organizational processes. The staff address the same criticism to the national health record, which presents the “raw” data, without valuation and architecture. The confess that they really would like to use it, but it needs to adapted to their working habits and oconstraints.
Need for coproduction of DHT

The results of the surveys highlight a growing interest for health data management and patients’ self-care, especially from the medical staff and Public Health authorities. On the other hand, elderly patients seem to have difficulties to “get digital” and to peacefully manage their digital health data. They need to be supported in the digital transition, in order to secure their digital health practices and to fully identify the gains of the DHT.

For an digital health innovation to be implemented and embraced by the users, it has:

- to fit in with existing practices, responding to needs, in order to make sense in daily health practices
- to create a break with the current uses, in order to legitimize their added value

It can be relied to a social and technological adaptation of Schumpeter’s “creative destruction”: eliminate obsolete uses by creating new ones.

Since now, according to the results, DHT seems to have been developed regardless the needs, the expectations, the constraints or the literacy levels of the targeted users. Concerning elderly people, most of the DHT are developed based on the developer’s representations of the skills and the needs of an elderly person, without concerns for the plurality represented by this population (Rivière & Brugière, 2012; Vigouroux-Zugasti, 2017).

The case of the French national health record is representative of the main problem that health professional highlight concerning digital health innovation. It is made by “administrative thinkers” (Mayday, 2016) who do not know the daily work of medical professionals.
The most relevant solution, according to researchers, patients and health professional, is to integrate the targeting audience into the development on a technological innovation:

- During the conception, to investigate the need and to define the goals of the DHT
- During the implementation, using prototypes, with testing users and focus groups
- During the evaluation process, after the product launch, to keep on improving it

In the case of DHT, there is a need for a quadripartite involvement, with, on the one hand, the medical staff and the patients who advise their needs, expectations and skills to the developers of the DHT, in order to promote its efficiency, especially concerning data accessibility and valuation. On the other hand, Public Health authorities must work hand-in-hand with the developers to insure the security of health data and the respect for European data policies.

Concerning the elderly people’s social and technical access to DHT, the problem is even more complex, as it requires a profound change in national public health policies. The social and technological mediation are the main key resource, as it helps elderly people improve their digital literacy level and make them control their digital environment / health data management. However, this kind of mediation cannot be done on digital platforms. It requires the set up of workshops, involving dedicated staff.
Discussion

The current pandemic context highlights the lacks in the health digitalization policy promoted for the last few years. The main technologies which have been developed seem to struggle to convince elderly users, as they do not correspond to their level of digital health literacy skills. Medical staff make the same observations concerning the national health record and try to find some alternative solutions to face the situation (strong extra-organizational relationships, strict data management policy, etc.).

The context is all the most paradoxical that the need for digital health technologies has never been as urgent, whereas it is currently dangerous to develop workshops and digital mediation, because of the respect for social distancing.

However, it would seem relevant to invest in the intergenerational relationships of older people to promote digital health practice. Several researchers have shown the influence of the digital uses of children and grandchildren on the evolution of elderly’s acculturation to digital technologies (Caradec & LeDouarin, 2012; LeDouarin, 2014). In this very particular context, maybe it would be efficient to mobilize elderly’s informal relationships to initiate / deepen digital health transition, and help elderly’ to better their digital health management. In this way, it would seem easier to get them involved in future digital health innovations.
Thank for your attention

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Panelist Position

Qualitative methods and Data Analytics: rich descriptions of Interactions of practitioners using videoconferencing

Qualitative Data Analytics of Interactions in Remote Medicine

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• Collaboration among practitioners using videoconferencing
• Qualitative methods: interaction analysis
• Analysis of knowledge sharing
• Expanding practice
• Remote medicine: New trajectories of patient treatment

→ Qualitative methods enable rich descriptions of videoconferencing in practice
→ Interaction analysis explore knowledge sharing and learning opportunities
  → Learning create new work practices
Qualitative Data Analytics of Interactions in Remote Medicine

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Interaction in remote medicine - examples

Remote specialist supports local surgical team

Remote specialist team supporting local general practitioner
Qualitative data

- Ethnographic study of collaborative work
- Search for an understanding of the organization of social actions
- Video recorded observations
- Transcriptions
Data collection

• Camera capturing the interaction and medical talk

• Interaction analysis, a strategy used in empirical investigation of talk, nonverbal interaction, and the use of artifacts in the interactions among people and objects in daily practice

• Content analysis of interaction and/or talk

Rich descriptions of knowledge sharing

Example of conversation between general practitioner and specialist team at hospital

<table>
<thead>
<tr>
<th>Table 5: Extract Tuesday, June 12</th>
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<tbody>
<tr>
<td>Consultation about treatment</td>
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<td>17 GP*</td>
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<td>33 GP</td>
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GP: general practitioner
S1: specialist 1
S2: specialist 2

Interaction analysis

Dilemma: The CRP level that had gradually declined now increased

- U17: the GP questioned this development as a dilemma in how to treat the patient. A query for specialist knowledge
- U20: The specialist recommended treatment, suggesting that the GP look for underlying reasons for the problem
- U21: A second specialist supplemented with general knowledge about the effect of kidney stones and the problem of getting rid of the infections and then recommended referring the patient to the hospital
- U25: This specialist explained a projection of the situation and suggested an x-ray to aid in diagnosis
- U28: The GP pointed out the existing x-ray and asked if a new x-ray would solve the problem. The specialist explained that several x-rays might not change the results, so the GP decided to reconsider the situation in a few days [U21]
Expanding practice

Activity on two levels:

The GP gave information about the patient’s biomedical history and asked the specialists for information to close the knowledge gap between them.

The specialist explained the effects and recommended treatment, providing the GP with the knowledge to consider the situation and make the decision(s) to wait.

A query for specialist knowledge

Included several specialist

Illustrated how their talk drew on different knowledge repertoires
Remote medicine: New trajectories of patient treatment

- create a shared medical practice
- in the boundary zone
- knowledge from different activity systems constituted a place for learning and development
Qualitative methods

• Enable rich descriptions of videoconferencing in practice
• Interaction analysis explore knowledge sharing and learning opportunities

Learning create new work practices
Thank you!


A System for Collecting Motion Data for Use in Quantitatively Evaluating Activities of Daily Living

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• Activities of daily living (ADL);
• Quantitative evaluation of ADL levels;
• Automatic and remote collecting system for motion data;
• Motion sensing;
A system is needed for quantitatively evaluating the activity recovery level of functional disable people.

Some patients who have recovered function in a rehabilitation facility are still unable to perform daily activities at home.

Recovering activities of daily living (ADL) has become more important than functional recovery.

Existing ADL recovery level indices are based on responses to questionnaires, judgment of recovery level is easily affected by an evaluator’s subject.

Developing a system for collecting and storing motion data on daily life activities for use in quantitatively evaluating ADL recovery levels.

Evaluation of the system using data measured for a healthy participant with restricted movement and two actual hemiplegic patients demonstrated that slight differences in disability levels can be detected.

This system is thus well suited for quantitative ADL assessment for patients with a disability.
System implementation

- **PatientApp:**
  - managing sensor devices;
  - getting measured data from sensor devices;
  - uploading the data file to the DataCollectionServer.

- **DataCollectionServer:**
  - managing user identification and user profile data;
  - registering measured data with a database and preserving it to the storage;
  - providing measured data file to authorized persons.
PatientApp

Login
UID: Patient’s name
PW: Anonymous

List of setting up
Patient’s name: Yoshitoshi Murata
Sensor 1: Wrist
Sensor 2: Lumbus
Beacon 1: Dinning table
Beacon 2: Toilet
Video: ON

[Transitions of UI pages]
[Example of setting up page list]
Data upload function:
The sensor relay unit temporarily stores measured data and forwards them to the server.

Data download function: Authorized persons, such as medical doctors can access the DataCollectionServer and download measured data files securely.
Sequence flow to upload measured files

1. PatientApp requests Client Sign In
2. Anonymous Login
3. Auth Sign In
4. Request Client Sign In
5. Anonymous certification
6. Uploading files and generating download file URL
7. Save file (Result)
8. Manage Download file URL in the Realtime database
9. /patients/{uid}/logs/{timestamp}/{filename}
10. Save Success?
11. Generate File Download URL
12. File Download URL

FirebaseAuthentication FirebaseRealtimeDatabase Storage
Appearance of the developed wearable device

**LSM6DSL**, STmicro

**HRM106Z**, Hosiden

- Acceleration sensor
- Gyro sensor
- Switch
- Bluetooth and CPU
- LED
- Battery CR2032
Measured data of restricted motions

[Wearable device] [Participant with sensors and restrictions]

[Bruising] [Face washing] [Eating]
Data of brushing
Data of face washing
Data of eating
Measurement for hemiplegic patients
Data collected walking

(a) Hemiplegic patient A

(b) Hemiplegic patient B

(c) Healthy participant
Data collected drinking

(a) Hemiplegic patient A
(b) Hemiplegic patient B
(c) Healthy participant
A system for collecting and storing motion data about daily life activities for use in quantitatively evaluating ADL recovery levels is developed.

Measured data for a healthy volunteer with restricted movement:
- It is possible to detect slight differences in the restriction level.
- It is difficult to estimate whether the motions can be performed without help.

Measured data for hemiplegic patients:
- The proposed system can collect motion data safely and smoothly;
- It is possible to detect slight differences in the severity.

Conclusion
The Importance of Motion Analysis and Physical Activity Measurement in Rehabilitation Treatment

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The importance of physical activity

- The Global Recommendations on Physical Activity for Health published by the WHO in 2010 identified “Physical Inactivity” as the fourth leading risk factor for global mortality.

  World Health Organization. Global Recommendations on Physical Activity for Health. 2010

- Increasing physical activity is essential for maintaining and promoting health and prolonging lifespan (Maintaining physical and cognitive functioning and preventing the development of new diseases, etc.).


- The one of purpose of habilitation treatment is to improve physical functioning, activities of daily living (ADL), and increase the quality of life in patients with physical disabilities.

- Therefore, to evaluate motion of ADL and physical activity is so important.

- We reported that motion analysis during drinking in hemiplegic patients using the system we developed in previous conference (eTELEMED 2019) and changes of ADL and physical activity in in this conference (eTELEMED 2020), respectively.
We developed a data collection system in which movements are analyzed using Google Firebase service and a wearable device equipped with a gyrosensor.

Popularizing this system will lead to big data, which could potentially establish evidence of many issues from physical activity levels during hospitalization and after discharge.

In fact, we measured 2 hemiplegic patients and 1 healthy participant during drinking using this system.

 Movements on shoulder abduction and trunk flexion were larger and time was longer on paretic side compared with non-paretic side in each hemiplegic patient.

 On the other hand, Similar motion between right and left sides showed in healthy participant.
Eight inpatients undergoing intensive rehabilitation treatment at Iwate Medical University Hospital participated in this study.

Physical activity levels were measured for all participants using small activity monitors with internal triaxial accelerometers two times with an interval of one week between the measurements.

Physical activity was measured continuously for twelve hours from 8:00 a.m. to 8:00 p.m.
Steps and walking time increased significantly after one week compared to the initial measurement (Steps: P = .012; Walking time: P = .036).

Time spent standing, sitting, and lying down was not significantly different after one week (standing: P = .208; sitting: P = .779; lying down: P = .575).

There was no significant correlation between BI variability and variability in steps and walking time.
Physical activity measurement in the future

- Existing motion analysis equipment and/or physical activity monitors require professional staff and time to put on and can interfere with inpatient tests and bathing.

- Also, in case of subject who indicated specific motion pattern (walking with crutches or slowly walking, etc.), the data may be not correct in existing activity monitors.

- We assume that the reason that motion analysis of ADL and physical activity measurement never been popular in clinical situation is there is no device resolved above problems.

- We believe there is a demand for a device capable of easily measuring physical activity levels and/or motion of ADL in various patients.