Reflections on how patients can drive a needed cultural change to digital and sustainable healthcare.

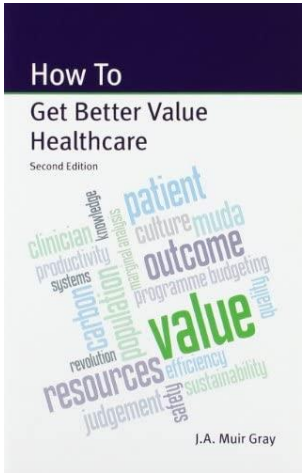
Ana Londral

6th SPX International Colloquium, Luxembourg
7/10/2025

value for health colab

A new revolution in healthcare?

- **séc. XIX**
  1st revolution in healthcare: Public Health
- **After World War II**
  2nd revolution in healthcare: Evidence-based paradigm
- **séc. XXI**
  A new revolution in healthcare: Value-based healthcare



And also, in a Cyber-Physical Society:

<u>A revolutionary shift in healthcare services, research and diagnosis...</u>

Ana Londral

Executive and Scientific Director at Value for Health CoLAB

Assistant Professor at NOVA School of Science and Technology, Lisbon, Portugal

Current opportunities and threats

- Life expectancy increase
- Tech innovation is providing amazing tools for healthcare at a fast pace
- Patients can develop digital tools, get involved in digital communities, access to information
- Strong pressure in sustainability of universal healthcare systems
- AI needs to gain trust and learn from all population
- Threat of *digital divide* and access to healthcare

In this cyber-physical society, how can we involve citizens to join and influence this “revolutionary shift” in healthcare?

What can we do?

*"**Efficiency** alone will not solve the problem of the next 30 years, namely closing the gap between need and demands on one side and resources on the other. To do that, we will need to shift resources from **lower value to higher value** healthcare."*

Adapted from: Muir, G., How To Get Better Value Healthcare (Offox Press, 2011)

*"The systemic process of identifying and reducing the use of **Low Value Care** is labeled as de-implementation; aka de-adoption, de-escalation, de-commission, and scale-down etc."*

Low Value Surgical Care: Are We Choosing Wisely?, Indian Journal of Surgery, Volume 85, pages 1017–1019, (2023)

Low Value Care

https://www.choosingwisely.org/

https://www.nice.org.uk/sharedlearning/nice-do-not-do-prompts

The term can be applied to:

- *diagnosis* (including unwarranted secondary tests for incidental findings),
- *treatment* (adverse events, poor patient outcomes, and over-treatment),
- *system-level delivery of healthcare* (inefficient use of resources threatening the sustainability of systems)

Shrank WH, Rogstad TL, Parekh N (2019) Waste in the US health care system: estimated costs and potential for savings. JAMA 322(15):1501–1509. https://doi.org/10.1001/jama.2019.13978

ValueS-based Healthcare

The EU Expert Panel's Report defines 4 aspects of value:

personal value - appropriate care to achieve a patient's personal goals
allocative value - equitable resource distribution across all patient groups
technical value - achievement of best possible outcomes with available resources
social value - contribution of healthcare to social participation and connectedness

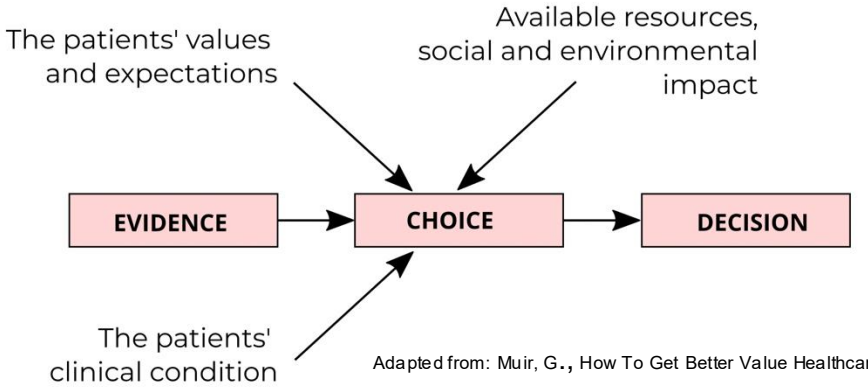
EXPH, 2019, Opinion on Defining value in "value-based healthcare"
https://health.ec.europa.eu/system/files/2019-11/024_defining-value-vbhc_en_0.pdf

European Commission

What matters to patients

*"Values-based practice in surgical care means **clinicians having the skills to engage in dialogue about values with their patients in shared decision-making** based on the available evidence-based options."*

https://valuesbasedpractice.org/values-based-practice-in-surgical-care-the-what-the-why-and-the-how/what-is-values-based-practice-in-surgical-care/



Adapted from: Muir, G., How To Get Better Value Healthcare (Offox Press, 2011)

Scientific community is concerned with building trust in AI

We specifically suggest (1) including patients with lived experience of the disease and carers, (2) creating an research advisory group and using these group meetings to involve patients and carers in all stages of the scientific process (starting from hypothesis generation).

Involving people in all aspects of AI development and deployment can potentially help humanize *AI. If AI is to have a bright future in society, we need to involve people in understanding and building AI.*

Banerjee, S., Griffiths, S. Involving patients in artificial intelligence research to build trustworthy systems. AI & Soc 39, 3037–3039 (2024).

High-value care needs real-world data

The value of a connected patient!

- empowered for self-care & telecare
- empowered for shared decision-making
- empowered to collect and report data
- empowers high-value care
- empowered to contribute and influence

Patient-generated health data

Londral A (2022) Assistive Technologies for Communication Empower Patients With ALS to Generate and Self-Report Health Data. Front. Neurol. 13:867567. doi: 10.3389/fneur.2022.867567

How can we involve patients on this “revolutionary shift” in healthcare and add their experience to digital innovation and datasets?

Some of our R&D projects

Cardio Follow.AI

A research study that developed and implemented a telemonitoring service for post-surgery surveillance.
https://cardiofollowai.vohcolab.org/

HOME-C2P2 Connecting care that counts

A European initiative to enhance home-based care and quality of life for children with complex chronic or palliative conditions.
https://home-c2p2.eu/

worthmed

Connects innovators, researchers, clinicians and patients to design, develop and validate digital health solutions. **https://worthmed.com/**

COM HOM

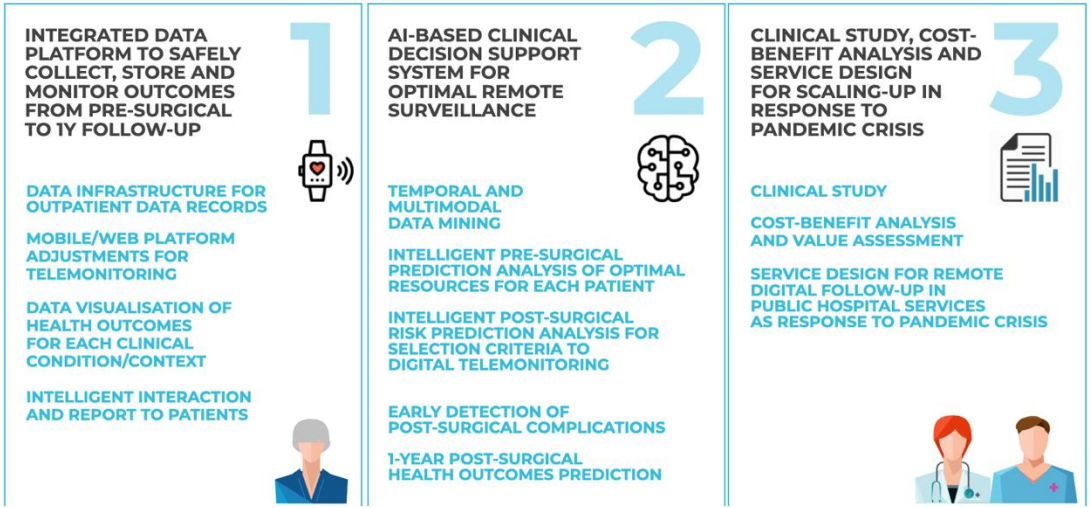
A Horizon Europe consortium for a comprehensive approach to Combating Homelessness through monitoring and evaluation, data-driven solutions and digitalisation.
https://comhom.eu/

Cardio Follow.AI

CardioFollow.AI

AN INTELLIGENT SYSTEM TO IMPROVE PATIENTS' SAFETY AND REMOTE SURVEILLANCE IN POST-SURGICAL FOLLOW-UP IN CARDIOTHORACIC SURGERY SERVICE - CENTRO HOSPITALAR UNIVERSITÁRIO LISBOA CENTRAL

2021-2024



A digital service for post-surgery

- We used participatory action research method to build, validate and scale-up the digital service.

- Engaging patients in self-report and self-care

- Engaging clinical teams in the digital service

- Effectively communicate outcomes to clinicians

- Effectively manage and register clinical support

A digital service for post-surgery


Londral et al. BMC Health Services Research (2022) 22:680
https://doi.org/10.1186/s12913-022-08073-4

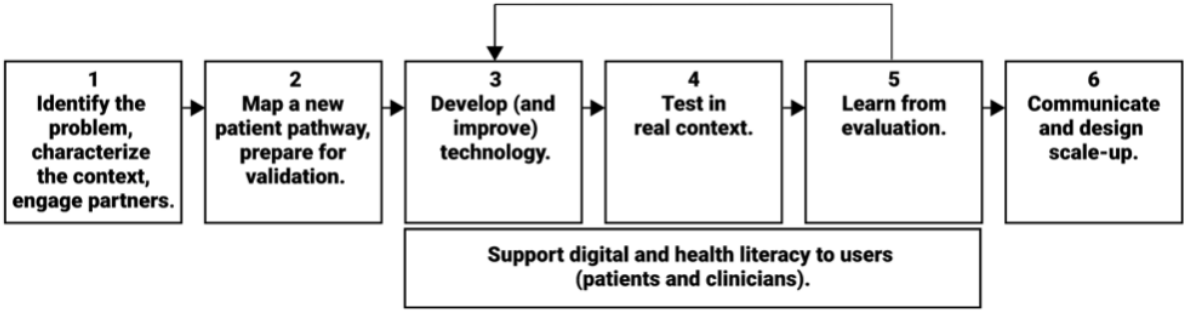
BMC Health Services Research

RESEARCH Open Access

Developing and validating high-value patient digital follow-up services: a pilot study in cardiac surgery

A. Londral[1,2*], S. Azevedo[1,2,3], P. Dias[1,2], C. Ramos[1,2], J. Santos[2,4], F. Martins[1,5], R. Silva[1,6], H. Semedo[4], C. Vital[4], A. Gualdino[4], J. Falcão[4], L. V. Lapão[2,7], P. Coelho[2,4] and J. G. Fragata[2,4]

Patient 0 > 5 patients > 10 patients > ~90 patients



Cardio Follow.AI

Develop with clinical teams and patients

Assess patient experience with interviews

Evaluation

Patient experience

We interviewed 26 participants after the 30-day telemonitoring period. It was not possible to interview 3 of the participants on the 30-day appointment at the hospital. This is justified by difficulties in coordinating the patients', clinical, and researchers' schedules. Nevertheless, these participants engaged in the whole telemonitoring process and reported data that supports this study.

From the responses to the three open questions, it was observed that ten patients (38%) explicitly reported that the remote monitoring allowed them to feel safer, with 3 (12%) referring to the relevance of the collected health data and 9 (35%) highlighting the support and interest demonstrated by the healthcare professionals in their recovery. Four patients (15%) reported difficulties in using the equipment related to taking the wound pictures. It is to note that the questions did not relate directly to the DHK but to what was most relevant in postoperative rehabilitation. Some statements of the patients that relate to the use of DHK are:

- *"I felt like I was at the hospital, that I was being accompanied by them all…"*
- *"Yesterday, I was thinking: when I get there to return the devices, I am going to have a surprise, they will give me one of this [referring to the DHK]…"*
- *"It is a friend that we do not see, but that is there with us every day [referring to the literacy messages in the chatbot]."*

Londral et al. BMC Health Services Research (2022) 22:680
https://doi.org/10.1186/s12913-022-08073-4

Simple universal methods to collect patient-reported experience/outcomes

Patient

Report outcomes and receive therapeutic adjustments from the doctor

Clinical team

Observe relevant outcomes and prescribe therapeutics.

Provide literacy instructions when needed.

Dehumanizing?

$$value = \frac{patients\ feel\ safe\ +\ high\ patient\ satisfaction\ +\ reduced\ critical\ incidences}{aprox.\ +280EUR}$$

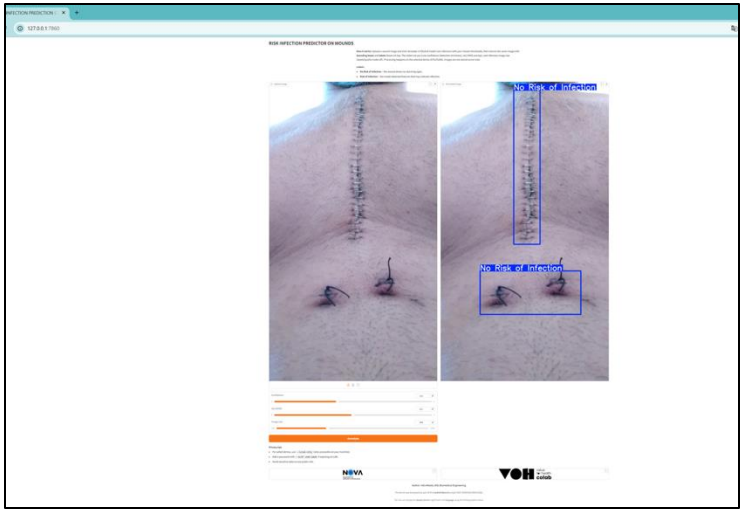
+ average ~8h/patient more attention from the clinical team in 30day follow-up

"There are several cases showing that telemedicine can be dehumanizing and dissocializing."

[Subtractive communication effects of telemedicine]

Matusitz, Jonathan, and Gerald-Mark Breen. Telemedicine: Its effects on health communication. *Health communication* 21, no. 1 (2007): 73-83.

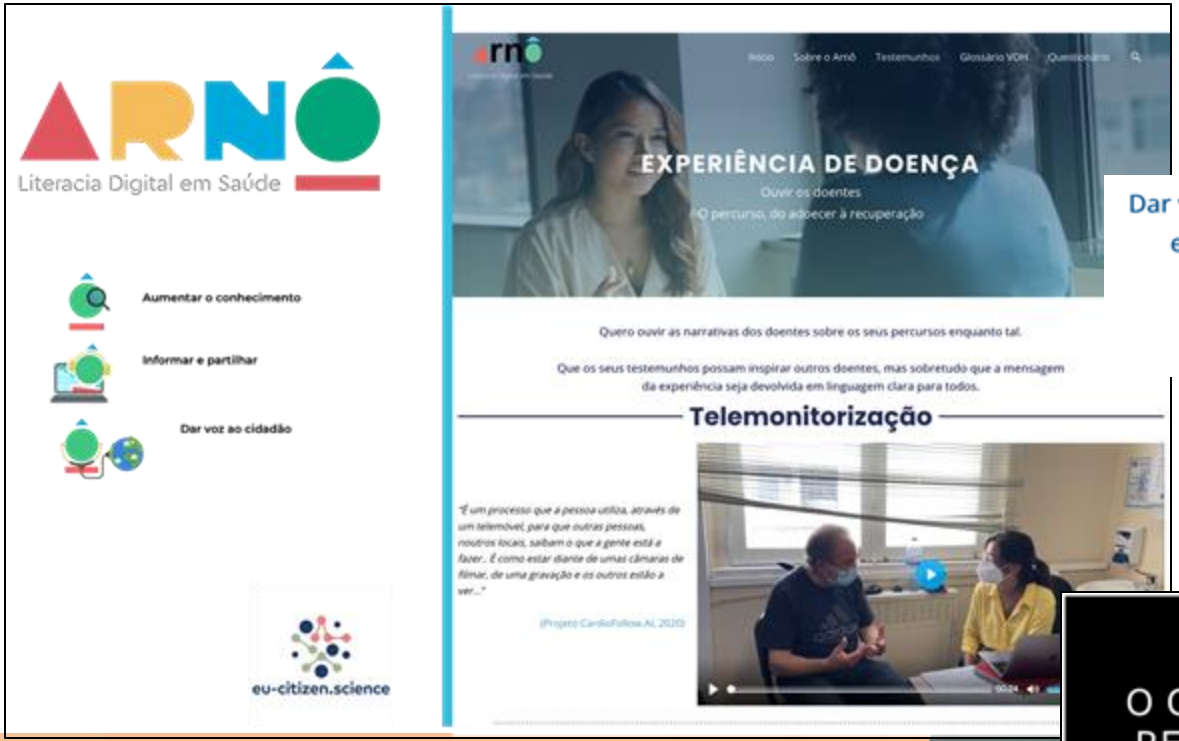
A risk predictor of surgical wound infection



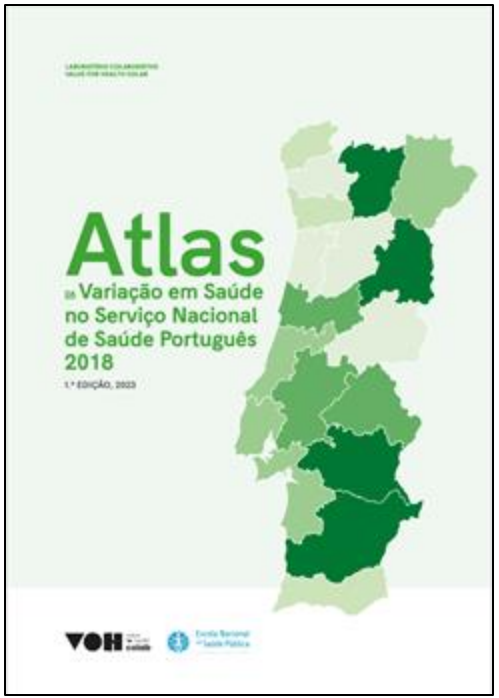
Cardio Follow.AI

- Based on a database of >1000 images collected by patients
- Collected daily in real-world environment (crowdsourcing)
- Annotated by nurses and doctors

Develop for citizens



Develop for citizens



HOME-C2P2

Project goal: Improve **home care for children with complex chronic conditions** through community and specialized care coordination and an enhanced IT-enabled coordination model.

Our Focus

- Put **children, families, and caregivers** at the centre of model refinement.
- Ensure their voices shape both the **care pathways** and the **evaluation tools**.

How do we collect patient experience data?

Metro Mapping (Stiggelbout et al., 2023)

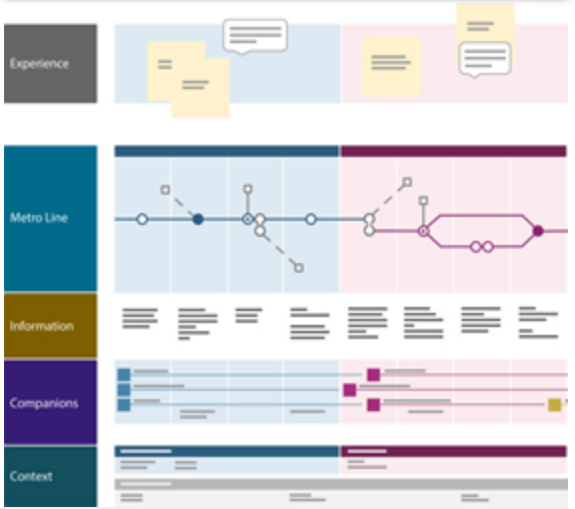
Mapping Patient Experience

"Stations" = critical touchpoints in the care journey.

At each station, we map:

- **What information is exchanged**
- **How and when it is delivered** (verbal, app, leaflet, telehealth)
- **How patients and families experience it** (challenges, information clarity, perceived supportiveness)
- **Who is involved** (professionals, companions)
- **Where it happens** (home, clinic, remote care)

Patient experiences are collected through interviews, focus groups, or observations, and illustrated with the main themes and quotes captured.



Stiggelbout, A. Et al. (2023). Metro Mapping: Development of an innovative methodology to co-design care paths to support shared decision making in oncology. *BMJ Evidence-Based Medicine*, *28*(5), 291–294. https://doi.org/10.1136/bmjebm-2022-112168

COMHOM COMPREHENSIVE APPROACH TO COMBATING HOMELESSNESS

Co-funded by the European Union

The COMHOM project has received funding from the European Union's European Social Fund (ESF) under Grant Agreement No. 101172624

Goal

Transform homelessness response through data, digital tools, and a standardised Monitoring & Evaluation (M&E) framework.

Approach

Implement co-creation through Living Labs, fostering collaboration to develop and test an AI-driven data platform with 25 EU social care organizations.

Outcomes

Strengthened social care service delivery, **better resource allocation**, and **improved support** for people experiencing homelessness.

CONSORTIUM PARTNERS

Metropolia · PRAKSIS · Simon Communities of Ireland · VOH colab · SJD Sant Joan de Déu Fundació de Recerca · SJD Sant Joan de Déu Serveis Socials · Barcelona · SJD Sant Joan de Déu València · CHINO.IO · European Social Network · socialIT software & consulting

ASSOCIATED PARTNERS

FEANTSA · SMES EUROPA · Y-Säätiö

COMHOM COMPREHENSIVE APPROACH TO COMBATING HOMELESSNESS

A COMHOM Living Lab is a “center without walls”

Where people with lived experience of homelessness, social care providers, psychosocial supporters, policymakers, and researchers **work together to co-create, test, and refine solutions for monitoring and evaluating homelessness** across Europe.

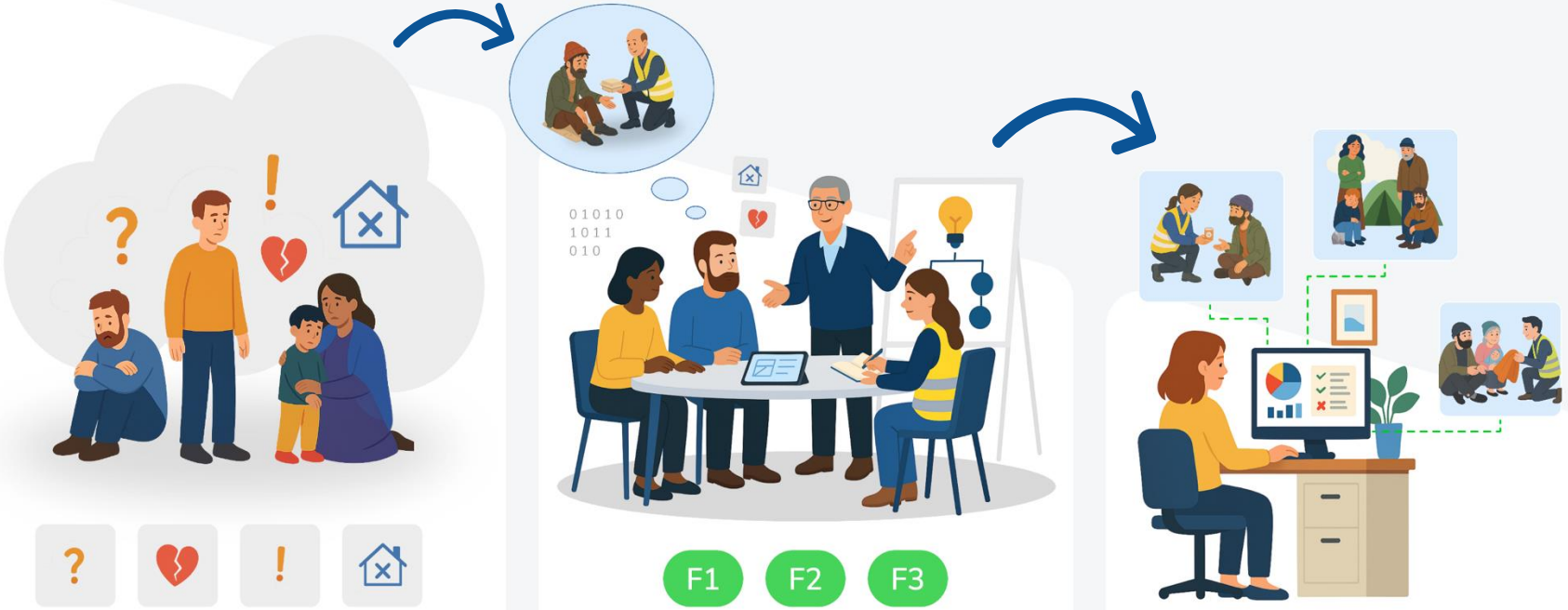
COMHOM Living Labs turn collaboration into action

COMPREHENSIVE APPROACH TO COMBATING HOMELESSNESS

Co-creating a digital solution through Living Lab sessions

In a Living Lab session, participants contribute with diverse perspectives, often stepping into different roles, to share insights, explore ideas, and **co-design a solution that reflects their real needs**. These sessions can range from **interviews to collaborative working sessions**.

How Do We Work?



1. CO-DEFINING THE HOMELESSNESS PROBLEM

Identify and filter real challenges around homelessness through community engagement and lived experience.

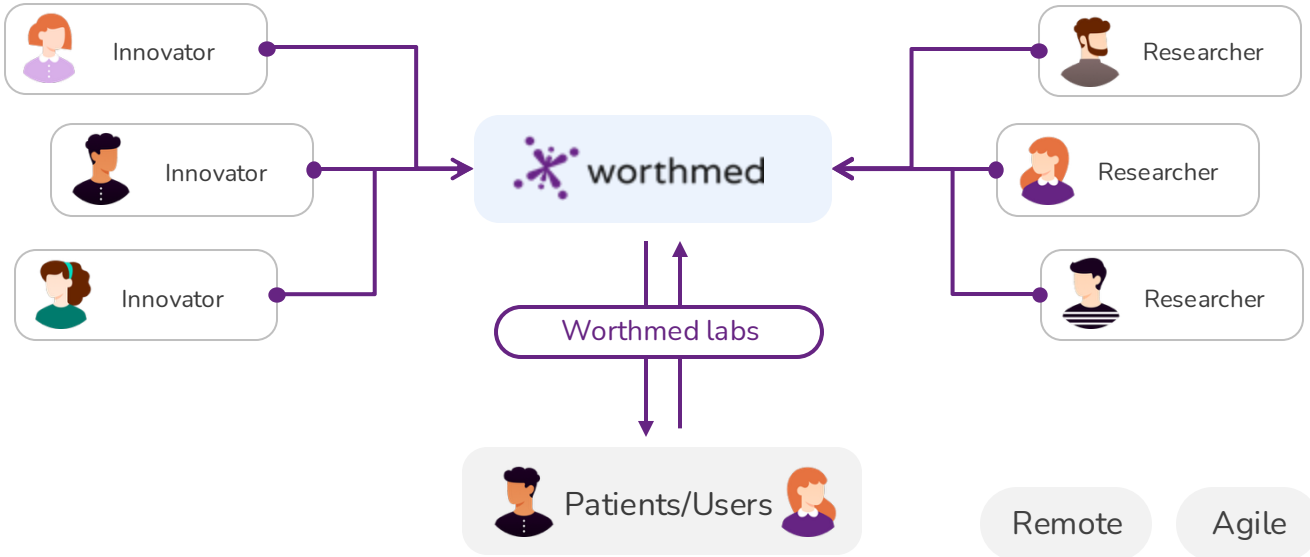
2. CO-DESIGNING A DIGITAL SOLUTION

Work with those affected by the identified problems to define solution features (F) and create a practical solution.

3. DEPLOYING THE DIGITAL SOLUTION

Test and refine the solution in real-world settings, including social care services.

Worthmed – online platform to support innovators in digital health



Remote

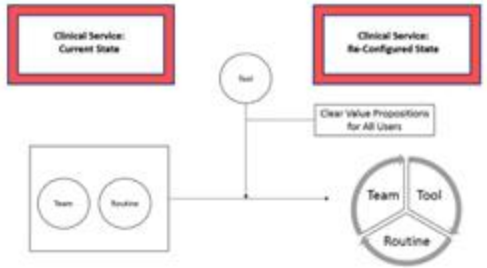
Agile

Collaborative

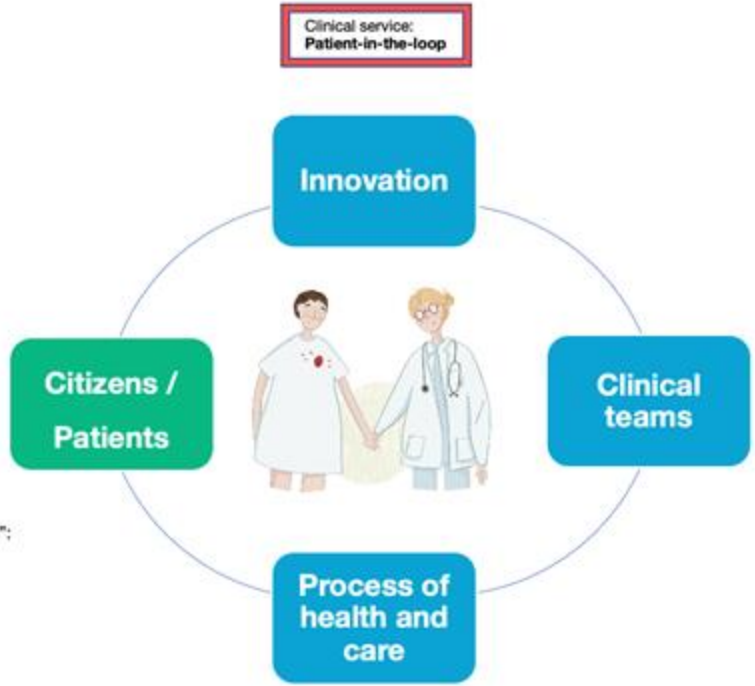
Bringing innovators and researchers together

Science-backed development | Worldwide pool of experts

Patients-in-the-loop



Shaw, J., Agarwal, P., Desveaux, L. *et al.* Beyond "implementation": digital health innovation and service design. *npj Digital Med* **1**, 48 (2018).



Develop with citizens

ACTION R&D
Participatory, collaborative and transdisciplinary research.
Agile prototyping in real-world contexts.

VALUE-DRIVEN HEALTHCARE INNOVATION
AI&data; Multi-stakeholder approach; decision analysis; outcomes research; economic evaluation; payment-model research.

Thank you for listening!

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