

Breakout session

Stakeholder engagement & communication

EDITH-CSA Final Ecosystem Meeting

15-16/07/2024

VPH Institute



EDITH is a coordination and support action funded by the Digital Europe program of the European Commission under grant agreement n° 101083771



Stakeholder Engagement



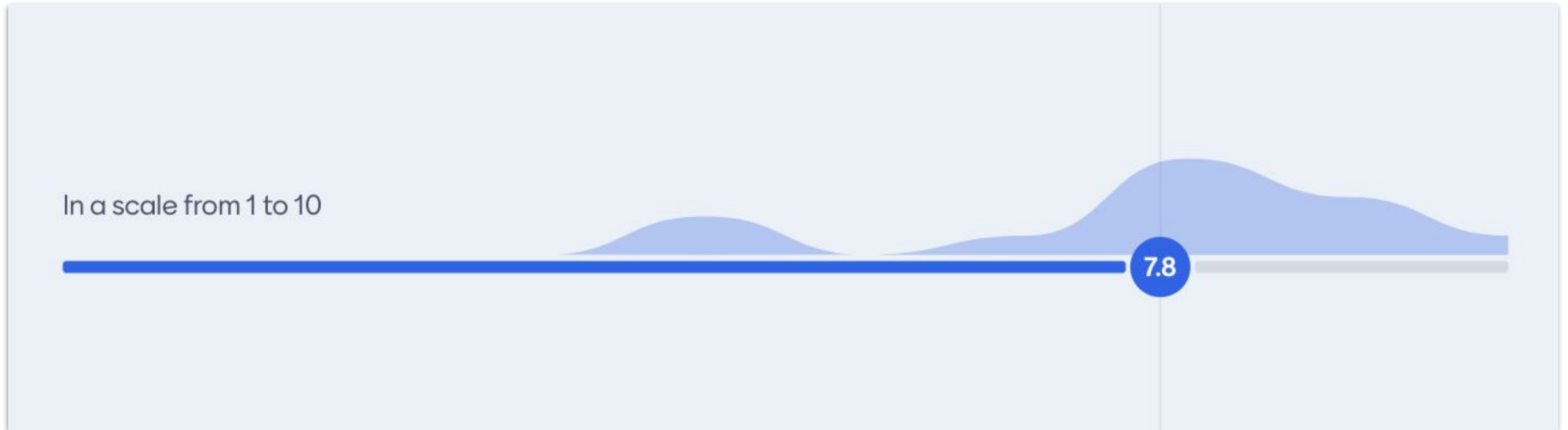
Action points:

- Feedback mechanism
- Joining forces
- Education
- Engage clinicians and lay people
- Tailor the language
- Stakeholder inclusion in R&I
- Constant feedback

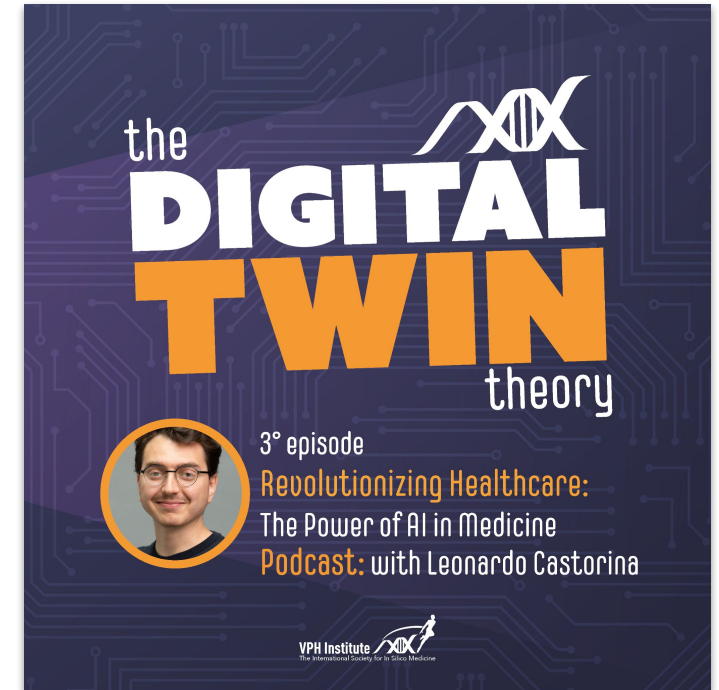
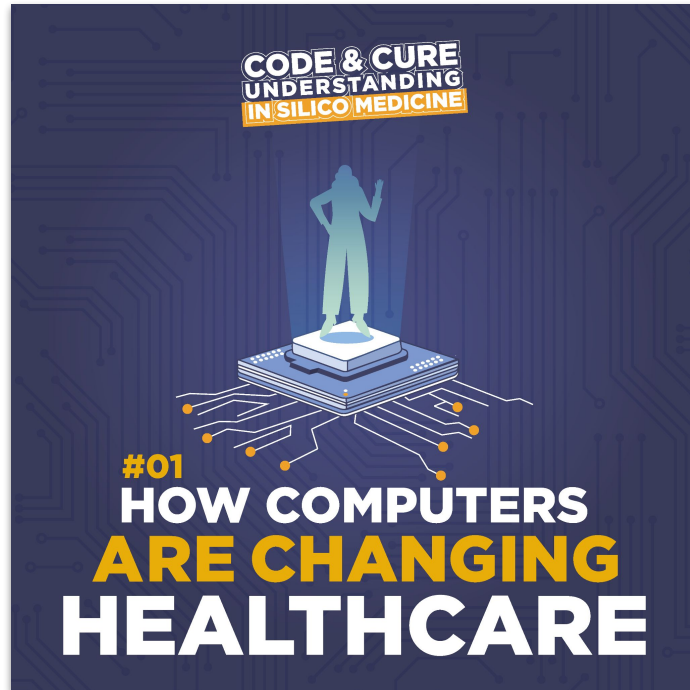


Communication & Dissemination

The importance of communication



The activities we conduct



Main points & Challenges

- Longer form content
- Tailor the language
- Finding the right balance engaging and not overselling
- Barriers as opportunities for growth
- How can we facilitate the flow between researches and communicators

1. How can we effectively empower and engage clinicians and patients?

2. How can we engage the VHT ecosystem in the communication process?

THANK YOU!





Goal of this session

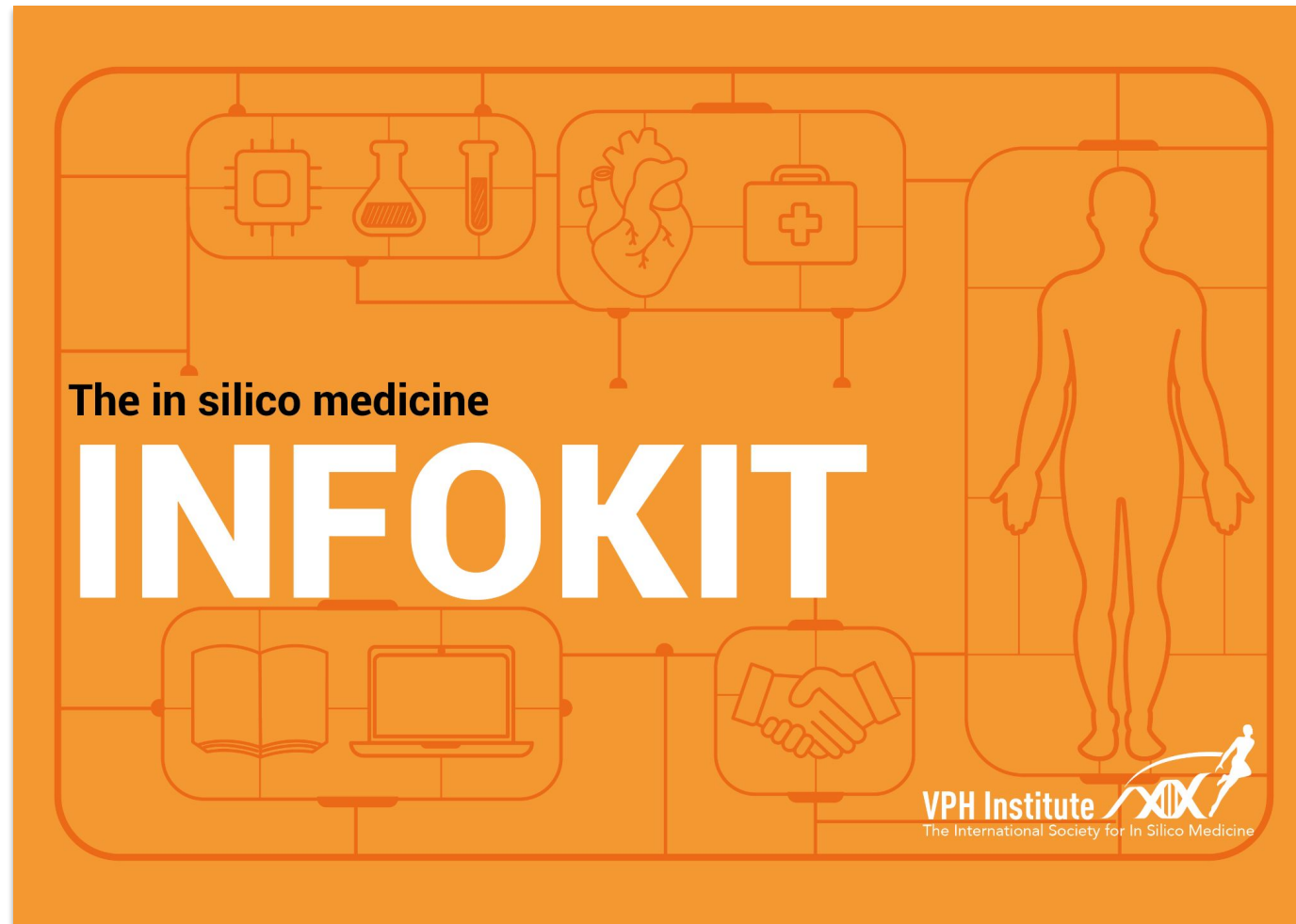
Brainstorm session about a stakeholder engagement & communication strategy for the VHT ecosystem based on learnings from the field of in silico medicine

1. Presentation & discussion of stakeholder engagement activities
2. Presentation & discussion of communication strategy

Context: chapter 7 roadmap (uptake of VHT)

What has been done so far in the ISM community? How can this be done for the VHT ecosystem?

What are we missing? What could work?



Stakeholder Engagement

Question 1: What comes into mind when you think about effective stakeholder engagement?



Why is stakeholder engagement important?

- Inclusion of stakeholders = alignment of R&I with different values, expectations, concerns and needs
- Inclusion of different perspectives/expertises → better research outcomes (co-creation)
- Uncovering of ethical, legal, and social implications (ELSI) of R&I
- Bridge the gap between those who 'make science' and those who 'reflect' on it
- More engaged public, responsible actors and institutions

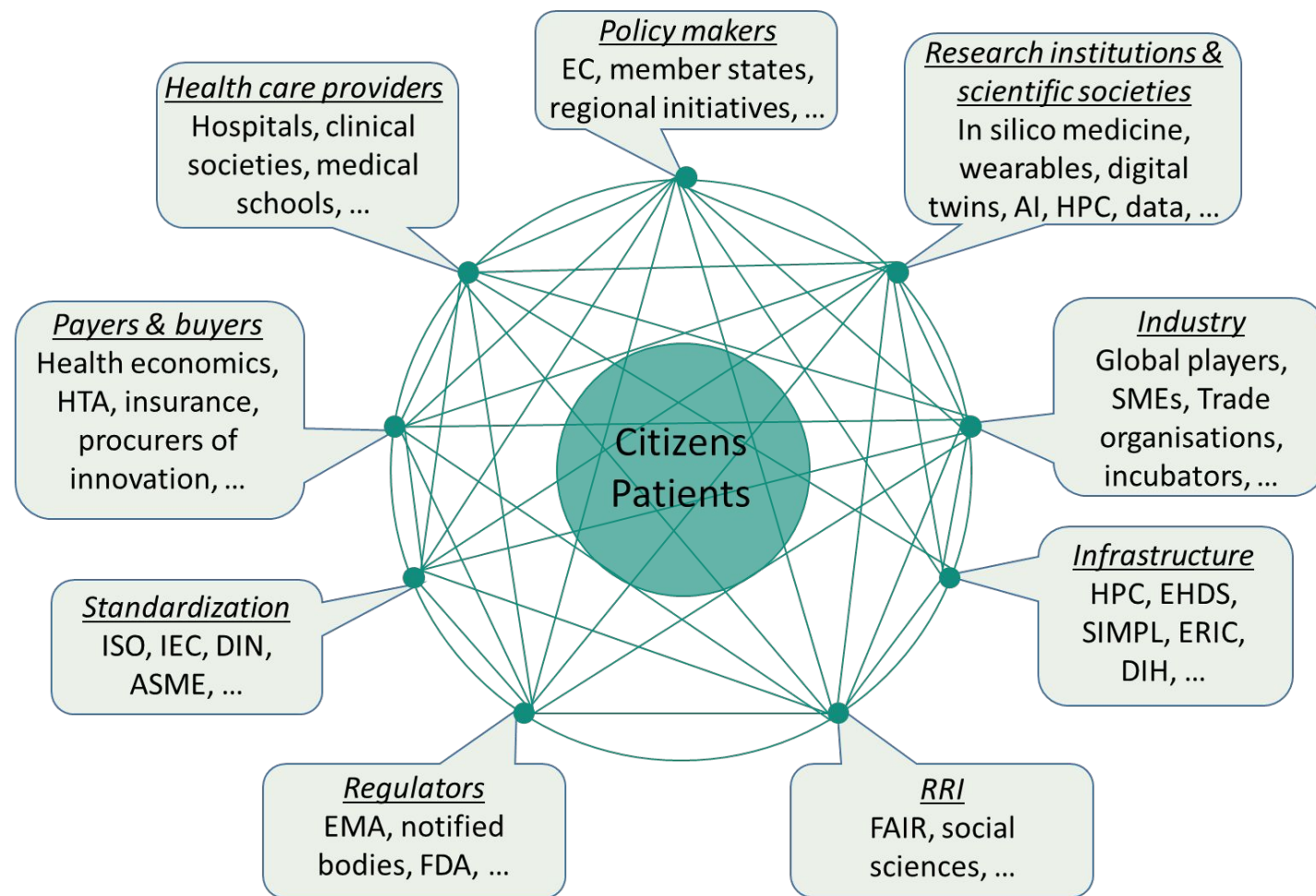
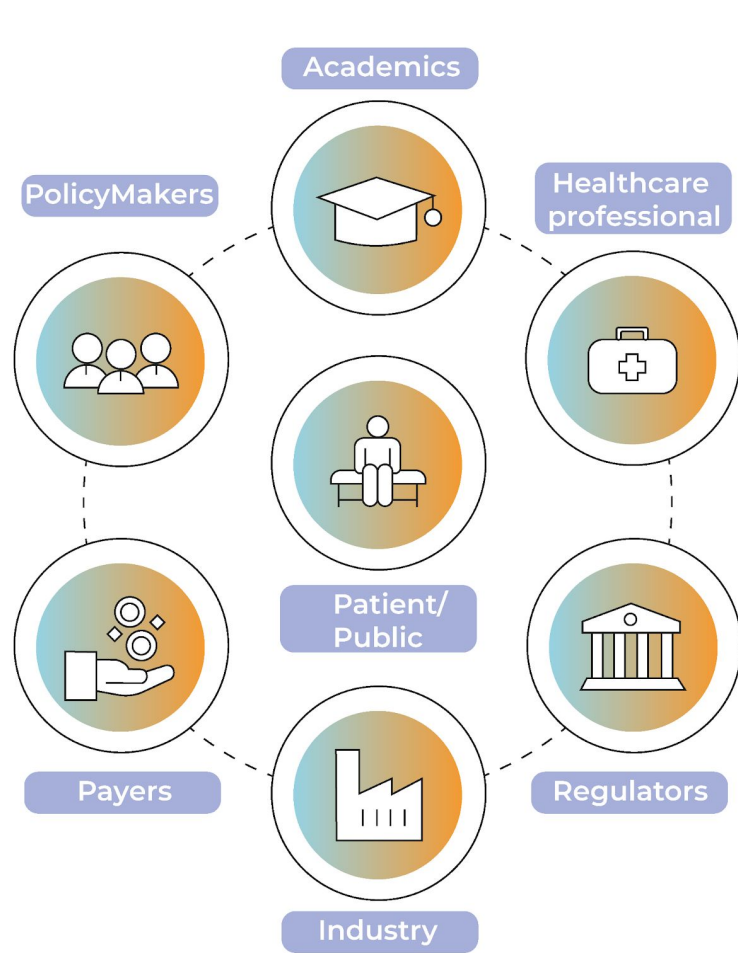
Stakeholder groups identified in ISW project



Ecosystem
for Digital Twins
in Healthcare

Ulrike Felt et al., "Doing Co-Creation: Power and Critique in the Development of a European Health Data Infrastructure," *Journal of Responsible Innovation* 10, no. 1 (2023), doi:10.1080/23299460.2023.2235931

Alba L'Astorina and Monica Di Fiore, "A New Bet for Scientists?: Implementing the Responsible Research and Innovation (RRI) Approach in the Research Practices," *Relations Beyond Anthropocentrism* 5, no. 2 (2017), doi:10.7358/rela-2017-002-last.



Question 2: What are the most important stakeholder groups for the VHTs?

Stakeholder groups identified in ISW project



Ecosystem
for Digital Twins
in Healthcare

Ulrike Felt et al., "Doing Co-Creation: Power and Critique in the Development of a European Health Data Infrastructure," *Journal of Responsible Innovation* 10, no. 1 (2023), doi:10.1080/23299460.2023.2235931

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Intensity of co-production in research projects

Co-production = range of practices at varied levels of engagement

Differing degrees of collaboration = different objectives

Intensity level of engagement	Description
Information	One-way communication (awareness-building events, glossary videos)
Consultation	Response-based communication (survey)
Collaboration	Participants having impact (focus groups, workshops)
Empowerment	Participants having decision-making capability

Brandt, P., Ernst, A., Gralla, F., Luederitz, C., Lang, D.J., Newig, J., Reinert F., Abson D.J. and von Wehrden, H. (2013) A review of transdisciplinary research in sustainability science, Ecological Economics, 92: 1–15. doi: 10.1016/j.ecolecon.2013.04.008

Level of stakeholder involvement	Format	Tools or resources
Information	One-way communication	Resource A: Unravelling the Science around in silico medicine Resource B: Glossary of in silico terminology Resource C: Multimedia resources Resource D: Success Stories & notable articles Position / White papers Information sessions
Consultation	Response-based	Tool A: How to conduct a Delphi Study? Tool B: How to conduct surveys?
Collaboration	Allows impact on R&I	Tool C: How to conduct focus groups? Tool D: How to organize an RRI workshop?
Empowerment	Allows decision-making	/

(Categorisations of involvement levels derived from Brandt. et al., 2013)



Intensity of engagement: consultation

Example: Clinical survey to assess the clinical community's opinion, knowledge, and concerns regarding the use of in silico methods in clinical practice

02. Survey objectives



Survey = useful tool to initiate engagement strategy

→ **identify action to take** (eg. create lecturing materials, more awareness-building, conduct follow-up focus groups/interviews)

PROS

- Surveys allow participants to remain **anonymous**
- **Cost-efficient** form of engagement (large group of respondents)
- Good tool to investigate first impressions on topic

CONS

- **Restricts in-depth inquiry**
- Suggestive questions can result in **bias**; the importance of effort in designing survey
- Likelihood of **dropout**
- Requires well-organized dissemination strategy
- **One-way** communication; impact on R&I= limited

Intensity of engagement: collaboration

Focus groups: multidisciplinary or per stakeholder group

- Group discussions (8-10 participants) about ethical, legal, and social implications (ELSI) of novel technologies = in silico medicine
- Understanding of the values/expectations/needs/concerns of the different stakeholders
- Fostering awareness of in silico medicine to the greater audience & allowing impact
- Multi-stakeholder approach allows for exchange of expertise (*clinicians, members of the public, patient representatives, ethics experts, SSH, etc.*)

How to organize a focus group

- Step 1: define objective/ research questions
- Step 2: identify participants (based on step 1)
- Step 3: practicalities (duration, structure, location, invites, voice recorder) + ethical approval
- Step 4: prepare materials (consent form, information sheet, voice recorder, printed materials)

Organizing Focus groups

Agenda: example

Welcome & Introduction [10 min]

Phase 1: Plenary lecture format

Topic 1: Introduction to *In silico* medicine in layman terms [15 min]

Topic 2: Introduction to aim and course of focus group [10 min]

Topic 3: Brief Q&A on set-up [15 min]

Phase 2: Round table discussion [1h 10min] (possible 10-min break)

Scenario 1: Focus card

Scenario 2: Focus card

Scenario 3: Focus card

Phase 3: Conclusion & wrap-up [5min]

Topic 1: Short conclusion

Topic 2: Expressing gratitude & acknowledgements



Organizing Focus groups

Card-based format: simplified scenarios or use cases, captured in easy-to-understand graphics to start the discussion.

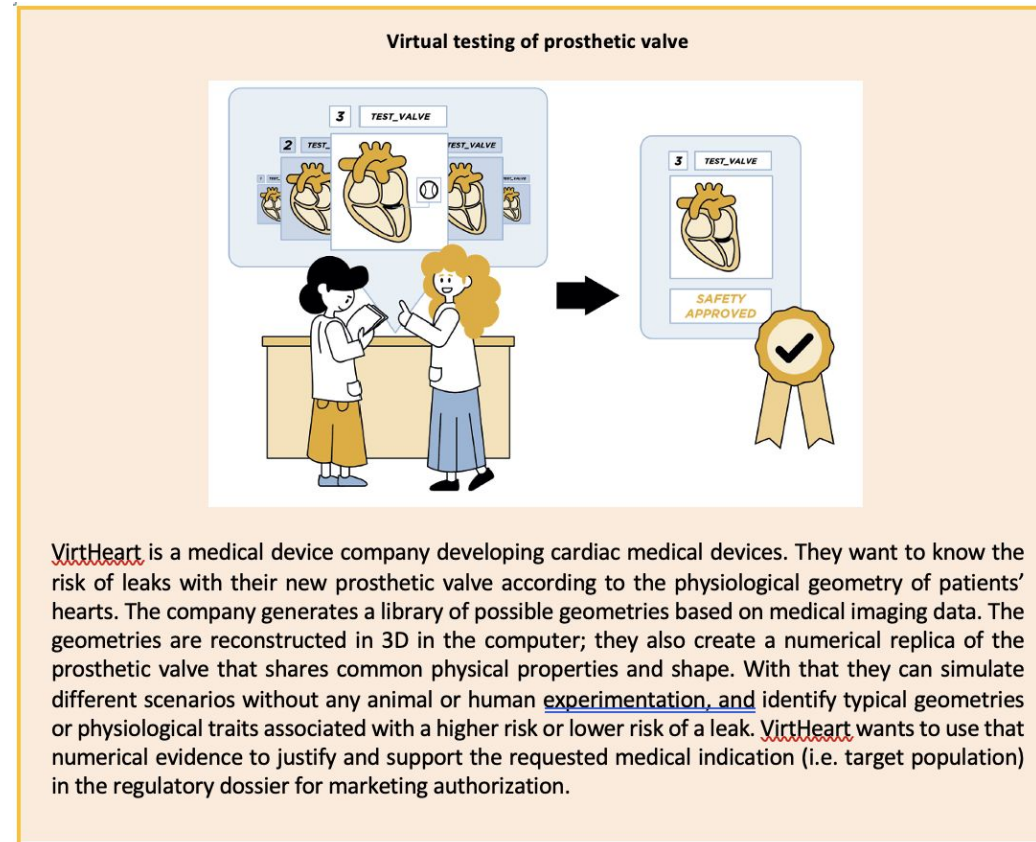


Table 2: "VirtHeart" scenario - Faster and safer testing of heart valves using in silico testing methods

Identified gaps for stakeholder engagement

Lack of awareness and familiarity

Definitional issues

Mismatched expectations

Lack of trust and trustworthiness

Changing landscape of expertise

Lack of trained workforce across healthcare ecosystem

Poorly informed stakeholders

⇒ How to tackle this?



Discussion via mentimeter



SMASH-HCM: hypertrophic cardiomyopathy DT

Towards GEMINI: A Generation of Multi-scale Digital Twins of Ischaemic and Haemorrhagic Stroke Patients

TARGET- Health virtual twins for the personalised management of stroke related to atrial fibrillation

VITAL - Virtual Twins as tools for personalised clinical care

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ARTEMIS - Accelerating the Translation of virtual twins towards a personalised Management of fatty liver patients



The In Silico World Project

Lowering barriers to the adoption of in silico trials

Project Coordinator: Prof. Marco Viceconti, University of Bologna, Italy
Communication Officer: Goran Stanic, VPH Institute, Belgium

Accelerating adoption of in silico trials

Currently, barriers still exist that delay the uptake of Computer Modelling & Simulation in all aspects of the health and care domain, including lack of publicly available reference data collections, insufficiently trained workforce and poorly informed stakeholders.

The In Silico World project aims to accelerate the uptake of modelling and simulation technologies for the development and regulatory assessment of medicines and medical devices with a long-term impact of reduction of the cost and duration of the development and regulatory assessment of new medical products while maintaining or improving the level of safety provided by conventional approaches.

Validation collections

There is a lack of publicly accessible curated medical data specifically designed for the development and validation of in silico trials technologies. That is why part of the In Silico World project focuses on collecting, sorting and publishing several data sets specifically designed to validate in silico trial solutions. InSilicoWorld, OpenVital and iThreat are already available on Zenodo.

Dataset	Accession Number	Accession Number	Accession Number
InSilicoWorld	10.5281/zenodo.1000000	10.5281/zenodo.1000000	10.5281/zenodo.1000000
OpenVital	10.5281/zenodo.1000000	10.5281/zenodo.1000000	10.5281/zenodo.1000000
iThreat	10.5281/zenodo.1000000	10.5281/zenodo.1000000	10.5281/zenodo.1000000

Stakeholder Engagement activities

It is crucial to give clear and correct information to all stakeholders (pharmaceuticals, patients, doctors, regulators, healthcare payers, Contract Research Organizations, technology providers, associations of biomedical companies, etc.) on the opportunities and the risks associated with the use of in silico trials technologies. It is also important to engage with all these stakeholders and involve them through a framework like responsible research and innovation (RRI).

The fundamental approach followed in the IW project to engage diverse stakeholder groups encompassed a series of steps (outlined for the different stakeholder groups with some adaptations), thus, understanding their needs, capturing their perceptions and collecting their concerns on in silico medicine.

Good Simulation Practice

IOW consortium brought together 128 experts in in silico trials working in academic, medical industry, regulatory bodies, hospitals, and consulting firms. Through a consensus process, these experts made the first attempt to define Good Simulation Practices (GSP) on how to develop, validate and use in Silico Trials. This resulted in the GSP Book, which has the potential to become an indispensable handbook for anyone who is planning to use in silico trials.

Advancing in silico solutions

The project advanced the development of 11 in silico trial solutions, designed to test the safety and/or the efficacy of medical devices, medical products, and even advanced therapy medicinal products such as tissue engineering constructs for regenerative medicine. The solutions target medical products to treat osteoporosis, tuberculosis, multiple sclerosis, coronary artery disease, central aneurysms, mammary carcinoma, and covid-19 infection, among others.

Toward Good Simulation Practice

Marco Viceconti, Luca Emiliani Editors

Handbook for the Regulatory Process of Biomedical Products

Education materials

To address the lack of trained workforce on in silico technologies, we have identified the learning needs of several stakeholder categories, such as engineering and medical students, or professionals active in relevant fields either with a medical, engineering or even legal background. Learning material is now being developed with a focus on offering it to an online self-learning platform. Lecture materials are being evaluated first in small groups of stakeholders, and then further refined.

INSILICO WORLD

VPH Institute
The International Society for In Silico Medicine

Avicenna Alliance
Association for Data Driven Medicine

Contact: goran@vph-institute.org

insilicoworld.com [linkedin.com/company/insilicoworld/](https://www.linkedin.com/company/insilicoworld/) [@insilicoworld](https://www.facebook.com/insilicoworld/) info@insilico.world

IOW project has received funding from the EU H2020 Research and Innovation Programme, under Grant Agreement n.101078503 © 2021 2025

Toward Good Simulation Practice

Best Practices for the Use of Computational Modelling and Simulation in the Regulatory Process of Biomedical Products

Marco Viceconti - Luca Emiliani Editors

- EDITH PUBLIC DISCUSSION CHANNEL
- IN SILICO TRIALS S.W.O.T. ANALYSIS CHANNEL

Communication & Dissemination

Communication towards lay publics

Question 10: How important is to you the communication of *in silico* medicine towards lay publics?

- Da 1 a 10

Communication towards lay publics

Question 11: How much time do you dedicate to communication activities? (hours/week)

- <1; 1-2; 3-5; 6-8; 8+

Communication towards lay publics

Question 12: Describe your reference public (Age)

- 10-14; 16-19; 20-29; 30-39; 40-49; 50+

Communication towards lay publics

Question 13: Describe your reference public (Education level)

- High-school diploma; BSc; MSc; PhD

Communication towards lay publics

Question 14: Do you use social media to communicate science towards a lay public?

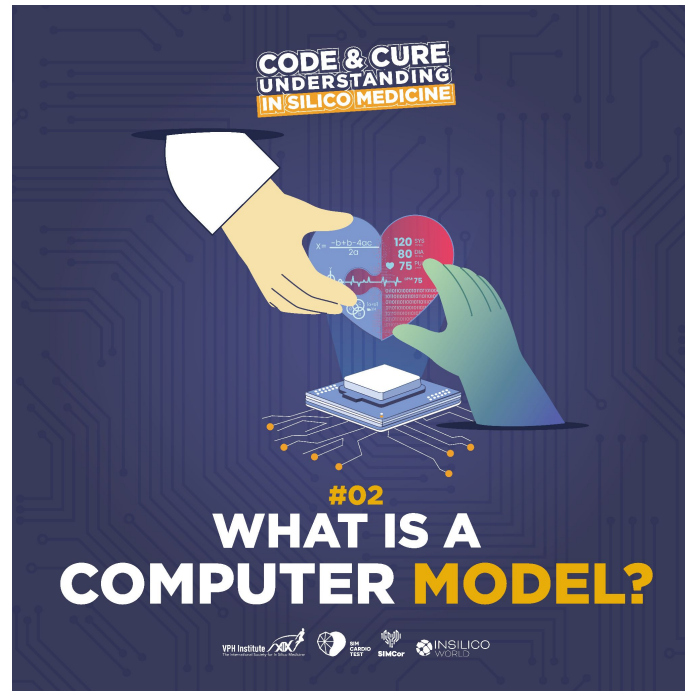
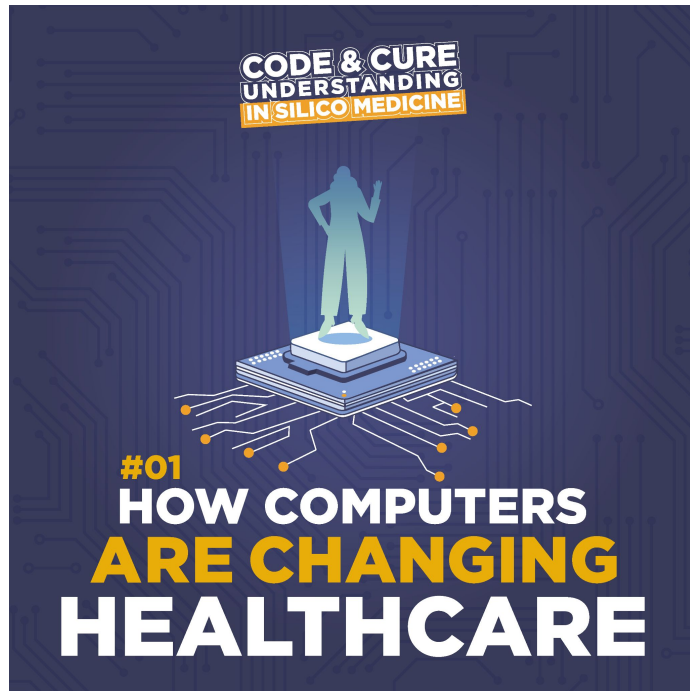
- Yes, No

Communication towards lay publics

Question 15: If yes, which is the main social media?

- Facebook, Instagram, LinkedIn, X, Threads, TikTok

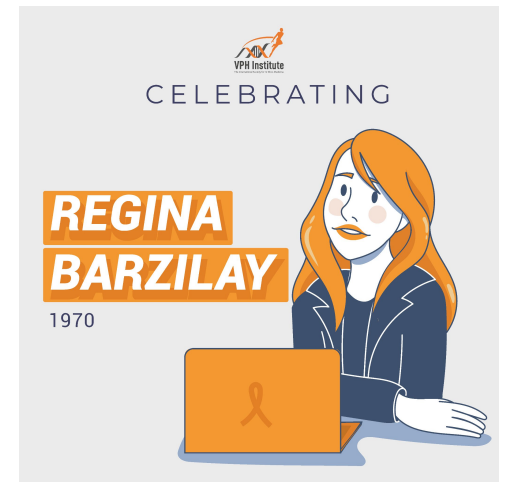
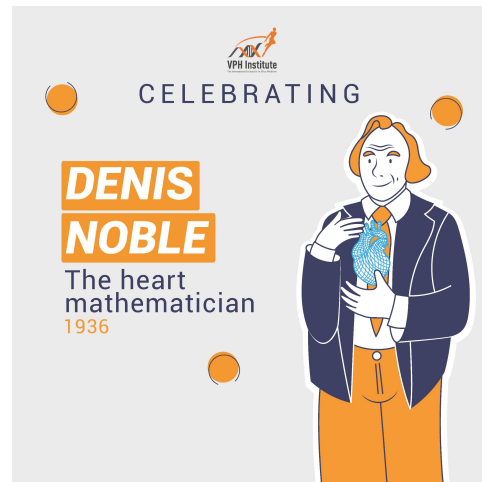
Examples (Animated videos)



Examples (Animated videos)



Examples (Characters)



Examples (Success Stories)

Revolutionizing liver surgery: How digital twins can reduce postoperative risks



Virtual Physiological Human Institute
2 min read · Jul 2, 2024

In silico trial predict phase 3 clinical trial result



Virtual Physiological Human Institute
3 min read · May 7, 2024

How computational models helped saving a clinical trial during the COVID pandemic



Virtual Physiological Human Institute
3 min read · Jun 3, 2024

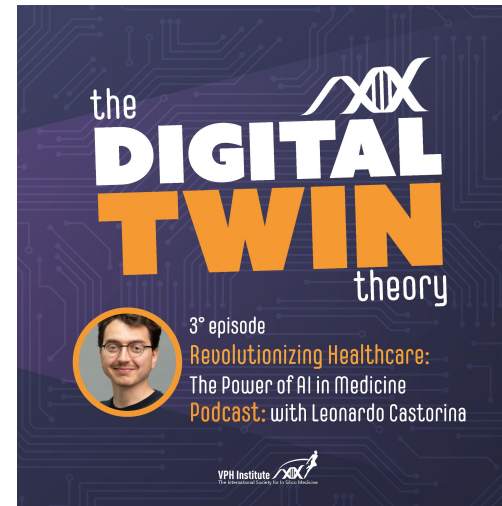
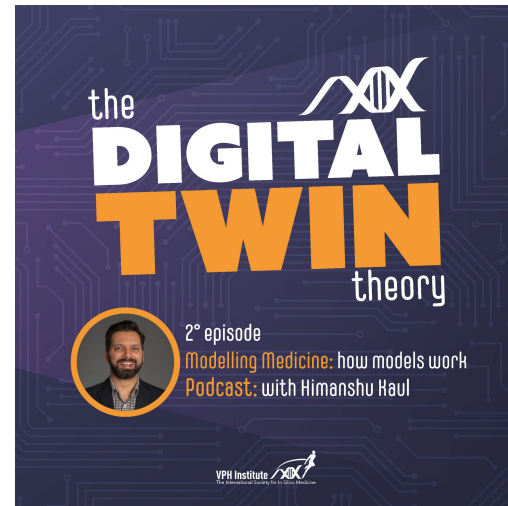


Ecosystem
for Digital Twins
in Healthcare

Question 16: Examples of success stories in the VHT



Examples (Podcast)



Communication towards lay publics

Question 17: Are there any further suggestions on activities that could be of interest for the public at large?

- Free discussion

Communication towards lay publics

Question 18: Where do you think there's more need to talk about Virtual Human Twin?

- TV, Radio, Podcast, Social Media, Newspapers/Magazines

Communication towards lay publics

Question 19: What is the desired outcome you would like to see?

- Free discussion

Education, Training and Re-training

How can we provide skills to different stakeholders in order to use, assess, develop VHT?

Education, Training and Re-training



1. ILO's WORKSHOP
 - Collect training needs
 - Group and prioritizing
 - Formulating of ILO (Intended Learning Outcomes)
2. Courses on ISM for technical and non-technical stakeholders
3. Production of Lecturing Materials
4. (Testing) TBD

THANK YOU!

Stakeholder engagement
& communication
amongst Sister projects

TOOL-05-03 Projects

SMASH-HCM: hypertrophic cardiomyopathy DT

Towards GEMINI: A Generation of Multi-scale Digital Twins of Ischaemic and Haemorrhagic Stroke Patients

TARGET- Health virtual twins for the personalised management of stroke related to atrial fibrillation

VITAL - Virtual Twins as tools for personalised clinical care

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ARTEMIS - AcceleRating the Translation of virtual twins towards a pErsonalised Management of fatty liver patients



Digital Twin & VHT Projects / industry / actors

- Team up on stakeholder engagement
'Together, we can get further'

But HOW?

- Joint newsletters?
 - Awareness campaigns?
 - Ideas?
- 