From Evidence to Implementation:

A Patient and Policy Perspective on Personalised Medicine

Bedo Taha BDS, MSc, PhD

European Alliance for Personalised Medicine

DIGICORE Connect to Win · Porto

Tuesday, 3 November 2026



European Alliance for Personalised Medicine

DigiCore

The gap between innovation and patient benefit

THE SCALE

2.7 million

estimated new cancer cases in the EU in 2024

TIMELY CARE

37% vs 74%

Lung cancer treatment started within 30 days of tissue diagnosis: Portugal vs Denmark

Data periods differ: 2019–21 vs 2022–24

THE PATIENT VOICE

1 in 3

patients surveyed reported no biomarker test before treatment

Sources: OECD / European Commission (2026), doi:10.1787/060869fe-en; Cancer Patients Europe (2025).



European Alliance for Personalised Medicine

DigiCore

Meet Claudia: where does personalised care break down?

A fictional patient journey

Claudia has been diagnosed with lung cancer. Her care team is considering a biomarker-guided treatment.

1



TESTING

Can Claudia access the right biomarker test in time?

2



INTERPRETATION

Can her team interpret the result and explain it clearly?

3



TREATMENT

Is the appropriate option available and accessible to her?

4



FOLLOW-UP

Are her outcomes and broader support needs being captured?



Evidence becomes patient benefit only when the pathway works.

European Alliance for Personalised Medicine

Connecting stakeholders to advance personalised medicine and patient access

Connecting across Europe

Examples of Alliance activities



Patients • Clinicians • Researchers • Policymakers • Regulators • Industry

Policy and implementation

- Diagnostics and IVDR engagement
- Biotech and patient access dialogue
- Beyond 1 Million Genomes project partner

Projects in focus

Sparc

precise

synthia

iBeChange

European Alliance for Personalised Medicine

Sources: euapm.eu | b1mg-project.eu

DigiCore

SPARC: personalised oncology in practice

Support of Personalised Medicine Approaches in Cancer

Sparc

The challenge: uneven access to molecular testing, clinical expertise and personalised care across Europe.

Harmonise diagnostics → **Strengthen clinical decisions** → **Advance equitable implementation**

36 months	**17 partners**	**€3.75m**	**€3.00m**
Nov 2025 – Oct 2028	8 EU countries	total budget	EU contribution

Coordinator: Universidad Politécnica de Madrid | **EAPM:** WP9 dissemination and policy outreach

European Alliance for Personalised Medicine

Sources: sparc-project.eu | European Commission, SPARC

DigiCore

How SPARC works: from evidence to implementation

Work packages and methods

Sparc

WP2 · Evidence
Systematic evidence review; NGS and liquid biopsy protocols; consensus methods

WP3 · Clinical pilots
Seven cancer pilots evaluate NGS and liquid biopsy workflows

WP4–5 · Clinical and digital tools
Molecular tumour board integration; digital and AI tool assessment

WP6 · Workforce
Training modules and certification approaches

WP7 · Patients
Co-created resources and stakeholder engagement

WP8–9 · Implementation
Equity and sustainability mapping; policy outreach and dissemination

Patient involvement and policy alignment connect the work packages



European Alliance for Personalised Medicine

Source: sparc-project.eu/about.html

DigiCore

Seven cancer pilots: specific use cases

Sparc

SPARC WP3 • planned diagnostic and monitoring approaches

1 

Lung
targeted NGS and liquid biopsy in stage III–IV NSCLC

2 

Breast
ESR1 mutations and resistance monitoring

3 

Pancreatic
liquid biopsy for monitoring

4 

Adrenocortical carcinoma
targeted NGS on liquid biopsy

5 

Neuroblastoma
ddPCR versus RT-qPCR for MRD markers

6 

Multiple myeloma
long-read whole-exome sequencing

7 

Melanoma
ctDNA assays for MRD during immunotherapy



Evaluation: feasibility · clinical utility · patient acceptance · implementation

SPARC | Patient input is now organised

Early implementation outputs

Sparc

JA PCM
Joint Action Personalised Cancer Medicine

37

PCAG members

Patient and Caregiver Advisory Group

Launched 21 May 2026



Published JA PCM–SPARC framework

1. Patient perspectives
2. Thematic working groups
3. Stakeholder engagement

Three working groups specified in the framework

- Liquid biopsy & NGS
- Molecular tumour boards
- Education & training

Patient input can now inform educational materials, guidelines and study information.

Reported outputs: an advisory group and a joint framework. Clinical pilot effects remain to be reported.

European Alliance for Personalised Medicine

Sources: SPARC Newsletter 3, July 2026; JA PCM D1.1, Zenodo 19206550 (24 Mar 2026).
Evidence checked: 30 Oct 2026.

DigiCore

BRECISE:
from biomarkers to clinical decisions

Biomarker Research and Evaluation for Clinical Implementation and Supporting Systems Enhancement

Many promising biomarkers face barriers to clinical validation, assessment and routine use.

Risk stratification › **Treatment response** › **Clinical implementation**

2025–2029 · 5 years | **25 partners · 15 European countries** | **€13.62m EU contribution**

Coordinator: South East Technological University, Ireland | **EAPM:** WP7 communication, outreach and capacity training

European Alliance for Personalised Medicine

Sources: brecise.eu | IHI project factsheet

DigiCore

How BRECISE works: evidence to adoption

brecise

Work packages and methods

WP2 · Requirements
Define use cases and platform needs

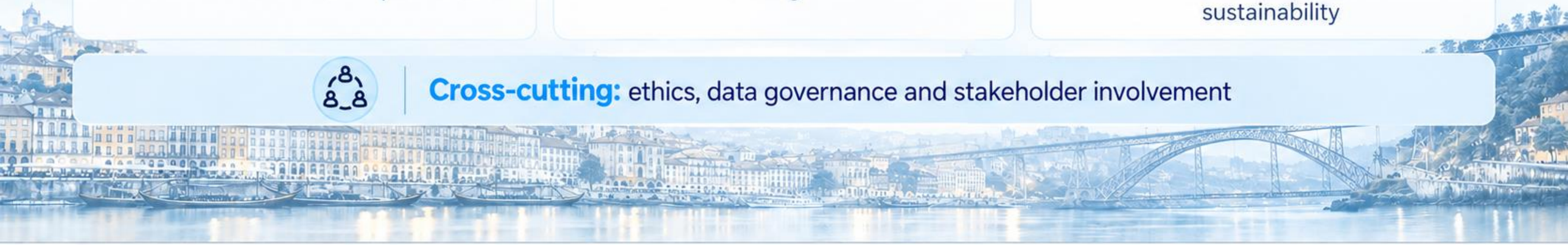
WP3–4 · Evidence
Molecular analysis, patient outcomes and biomarker evolution

WP5 · Ex vivo testing
Assess drug responses outside the patient

WP6 · Platform
Integrate clinical and biomarker data; support framework implementation

WP7 · Engagement
Communication, patient outreach and capacity training

WP8 · Adoption
Regulatory activities, health technology assessment and sustainability



Cross-cutting: ethics, data governance and stakeholder involvement

Five use cases, two cancer pathways

Four biomarkers and one clinical workflow use case

brecise

1 PROSTATE | **PDE4D7**

Progression risk in active surveillance



2 PROSTATE | **PCAI ImmunoScore**

Response to hormonal treatment



3 BLADDER | **BCAI ImmunoScore**

BCG response in high-risk non-muscle-invasive disease



4 BLADDER | **NOV I/O BC**

Immunotherapy response in metastatic disease



5 PROSTATE | **Workflow integration**

Clinical systems and predictive models



Under evaluation: clinical validity · patient outcomes · implementation

European Alliance for Personalised Medicine

Sources: brecise.eu | IHI BRECISE factsheet

DigiCore

BRECISE | From samples to usable evidence

Reported progress — July 2026 newsletter

brecise

47

bladder cancer organoid models established

33 additional models in progress

At the March 2026 London plenary

>40

organoid models DNA/RNA sequenced

At the March 2026 London plenary

79

patient and citizen education resources mapped

By patient organisations AIMAC and ELLOK

Clinical Data Lake operational

Secure, structured data exchange since February 2026.

PRECISE2 open for enrolment

Approved protocol for the liquid-biopsy immunotherapy study.

Enabling outputs are in place; biomarker accuracy and patient benefit remain under evaluation.

European Alliance for Personalised Medicine

Source: BRECISE Newsletter 2, July 2026, pp. 2, 4–5. Organoid figures: March 2026 plenary.
Evidence checked: 30 Oct 2026.

DigiCore

SYNTHIA: building trust in synthetic data

Synthetic Data Generation Framework for Integrated Validation of Use Cases and AI Healthcare Applications

The challenge: can generated data support research while meeting evidence, privacy and trust requirements?

Generate

Evaluate

Enable responsible use

2024–2029
5 years

39
consortium partners

€22.42m
total cost

€12.44m
EU contribution

Academic coordinator: IIS La Fe, Spain

EAPM: policy and dissemination partner

European Alliance for Personalised Medicine

Sources: cordis.europa.eu/project/id/101172872 | ihi-synthia.eu

DigiCore

How SYNTHIA builds assessable evidence

Work packages and methods

synthia

1. **WP3 · Clinical use cases**
   Define data and application requirements

2. **WP4–5 · Data and infrastructure**
   Standardise data; build federated platform

3. **WP6 · Generation**
   Develop synthetic-data methods and tools

4. **WP7 · Evaluation**
   Assess quality, privacy and clinical utility

5. **WP8 · Ethics**
   Address legal, ethical and societal issues

6. **WP9–10 · Decision-making**
   Regulatory and HTA work; policy engagement

Fit for purpose: value depends on the intended use

European Alliance for Personalised Medicine

Source: ihi-synthia.eu/synthia/work-packages

DigiCore

SYNTHIA | From generation to assessment

New technical outputs and mock HTA findings

synthia

6 clinical use cases

eCRF successfully deployed

Standardised multimodal data capture



Reported 27 Oct 2026

4 objects covered by the governance framework

- Source datasets
- SDG systems
- Synthetic datasets
- Publishing platform

Published 8 Oct 2026

2 hypothetical lung cancer submissions appraised

HTA & Regulatory Advisory Group | 18 June 2026

AI chest X-ray device

Caution: representativeness and independent real-data validation.

Indirect treatment comparison

More positive: fills a comparator data gap; technical validation still needed.

Assessment depends on intended use, added value, transparent validation and uncertainty.

Mock appraisal findings; no regulatory approval or reimbursement decision.

European Alliance for Personalised Medicine

Sources: SYNTHIA IHI Forum poster/news (27 Oct 2026); Governance framework, Zenodo 23237803 (8 Oct 2026); HTA Advisory Group report (2 Aug 2026). Evidence checked: 30 Oct 2026.

DigiCore

iBeCHANGE: personalised cancer prevention

iBeChange

Supporting sustainable behaviour change and emotional wellbeing

The challenge

Knowing what is healthy does not always make behaviour change easy to sustain.

- Smoking
- Alcohol
- Nutrition
- Physical activity
- Psychosocial health

2023–2028 · 5 years | **€5.75m EU funding** | **Horizon Europe · Cancer Mission**

Coordinator: European Institute of Oncology, Italy | **EAPM:** policy implementation and stakeholder engagement

European Alliance for Personalised Medicine

Sources: ibechange.eu | CORDIS 101136840

DigiCore

iBeChange

How the intervention supports people

A personalised, stepped-care approach under evaluation



1 Understand

Behavioural and emotional patterns



2 Personalise

Tailored behaviour-change and emotional-management strategies



3 Support

Digital guidance, with professional input when needed



4 Adapt

AI-informed recommendations and exploratory wearable monitoring



Designed to support sustainable changes in everyday life

European Alliance for Personalised Medicine

Sources: ibechange.eu · pilot announcement | CORDIS 101136840

DigiCore

From intervention to evidence

iBeChange

What iBeCHANGE is testing

Dec 2025

Pilot study began

Testing personalised digital support for behaviour and emotional wellbeing

1,800

planned users in a larger clinical study

Italy · Spain · Romania

Evaluation questions

- **Feasibility**
- **Usability**
- **Effectiveness**
- **Cost-effectiveness**



European Alliance for Personalised Medicine

Sources: ibechange.eu · pilot announcement | CORDIS reporting period 1

DigiCore

iBeCHANGE | Prevention built around people

Completed co-design and intervention outputs

iBeChange

67 focus-group participants

4 centres | May–July 2025

276 missions

431 recommendations

37 resources

What users prioritised

- Tailored goals and choice
- Credible, accessible information
- Human support

5 health pillars

- Smoking
- Alcohol
- Nutrition
- Physical activity
- Emotional wellbeing

Content clinically reviewed in Italian, Romanian and Spanish.
Completed design outputs; clinical effectiveness estimates not yet verified.

European Alliance for Personalised Medicine

Sources: iBeCHANGE D2.4 (4 Sep 2025), Table 1 and §4; D2.6 (29 Aug 2025), Table 1.
Evidence checked: 30 Oct 2026.

DigiCore

Four projects, shared implementation lessons

Sparc

Implementation and equitable access

PATIENT	Can I access personalised care wherever I am treated?
POLICY	What capacity and coordination support equitable delivery?

Brecise

Biomarkers that inform care

PATIENT	Will this biomarker improve my treatment decision?
POLICY	What evidence supports adoption, HTA and reimbursement?

synthia

Trustworthy synthetic evidence

PATIENT	Can synthetic evidence be trusted for people like me?
POLICY	When is synthetic evidence fit for assessment?

iBeChange

Prevention that fits daily life

PATIENT	Can prevention support fit my circumstances?
POLICY	How can digital prevention be accessible and sustainable?

Access • Clinical usefulness • Trust • Meaningful participation

Where these lessons meet DIGICORE's work

Three opportunities for collaboration

1



Define questions with patients

- Timely access
- Treatment burden
- Quality of life

Start with decisions and outcomes that matter.

2



Connect testing to care

- Biomarker result
- Clinical decision
- Patient outcome

Examine variation across centres and patient groups.

3



Build evidence for adoption

- Representativeness and uncertainty
- Resources and feasibility
- HTA and healthcare relevance

Make evidence useful for real decisions.

Across cancer centres, when does molecular testing change management—and which patients are still missing out?

Funding acknowledgements and disclaimers

Projects presented by Bedo Taha | European Alliance for Personalised Medicine

Sparc

EU4Health | Grant agreement No. 101232874

Co-funded by the European Union

FUNDING ACKNOWLEDGEMENT

SPARC is co-funded by the European Union's EU4Health Programme under grant agreement No. 101232874.

DISCLAIMER

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.

precise

IHI JU | Grant agreement No. 101194784

Co-funded by the European Union

innovative health initiative

Schweizerische Eidgenossenschaft
Confédération suisse
Confederazione Svizzera
Confederaziun svizra

COCIR Advancing Healthcare · efpia · EuropaBio

MedTech Europe from diagnosis to cure · Vaccines Europe

FUNDING ACKNOWLEDGEMENT

This project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No. 101194784. The JU receives support from the European Union's Horizon Europe research and innovation programme and COCIR, EFPIA, Europa Bío, MedTech Europe, and Vaccines Europe.

Funded by the State Secretariat for Education, Research and Innovation (SERI), Switzerland.

DISCLAIMER

Funded by the European Union, the private members, and those contributing partners of the IHI JU. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the aforementioned parties. Neither of the aforementioned parties can be held responsible for them.

SYNTHIA

IHI JU | Grant agreement No. 101172872

Co-funded by the European Union

innovative health initiative · DNV · UK Research and Innovation

COCIR Advancing Healthcare · efpia · EuropaBio

MedTech Europe from diagnosis to cure · Vaccines Europe

FUNDING ACKNOWLEDGEMENT

This project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No. 101172872. The JU receives support from the European Union's Horizon Europe research and innovation programme and COCIR, EFPIA, Europa Bío, MedTech Europe, and Vaccines Europe, and DNV.

The UK consortium partner, the National Institute for Health and Care Excellence (NICE), is supported by UKRI Grant 10132181.

DISCLAIMER

Funded by the European Union, the private members, and those contributing partners of the IHI JU. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the aforementioned parties. Neither of the aforementioned parties can be held responsible for them.

iBeChange

Horizon Europe | Grant agreement No. 101136840

Funded by the European Union

FUNDING ACKNOWLEDGEMENT

This project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No. 101136840.

DISCLAIMER

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HaDEA). Neither the European Union nor the granting authority can be held responsible for them.

From evidence to a better decision for the patient



Personalised medicine delivers value when:

Patients can access it.
Clinicians can use it.
Health systems can sustain it.

- Access
- Clinical usefulness
- Trust
- Sustainability

Thank you

Bedo Taha | European Alliance for Personalised Medicine

bedo.taha-eapm@euapm.eu