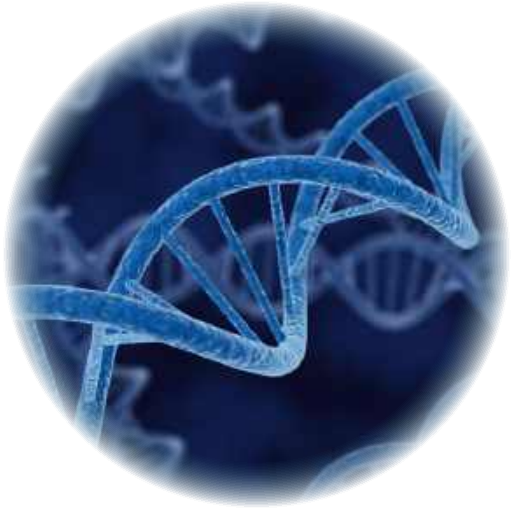
The Patient Expert Center

PATIENT EXPERT CENTER



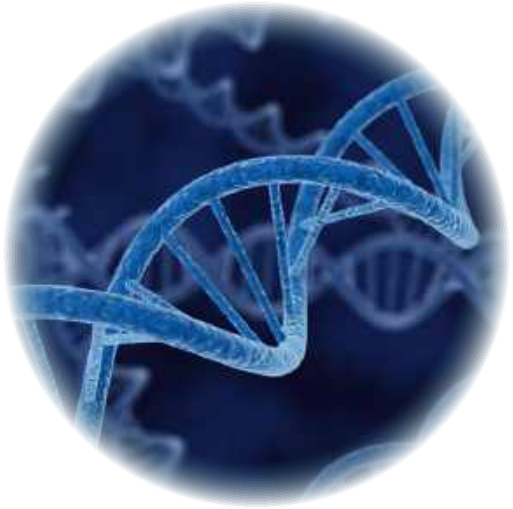
The patient challenge



Biology

The patient challenge

PATIENT EXPERT CENTER



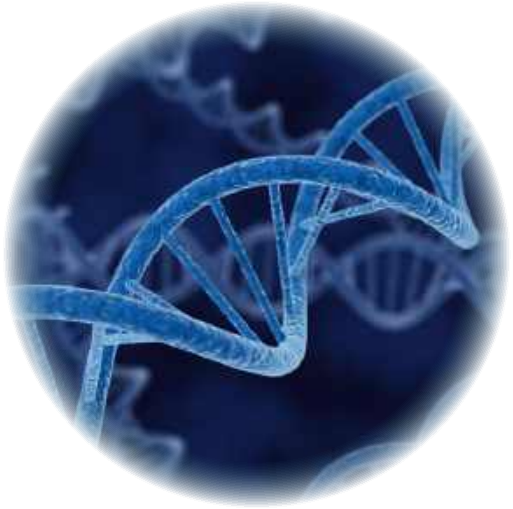


Biology

Technology

The patient challenge

PATIENT EXPERT CENTER



Biology



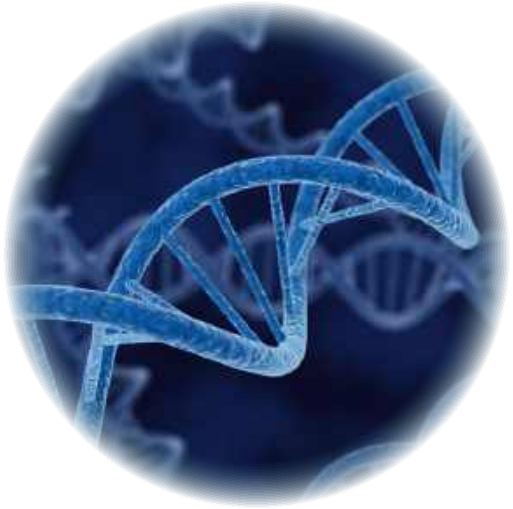
Technology



Cathy

The patient challenge

PATIENT EXPERT CENTER



Biology



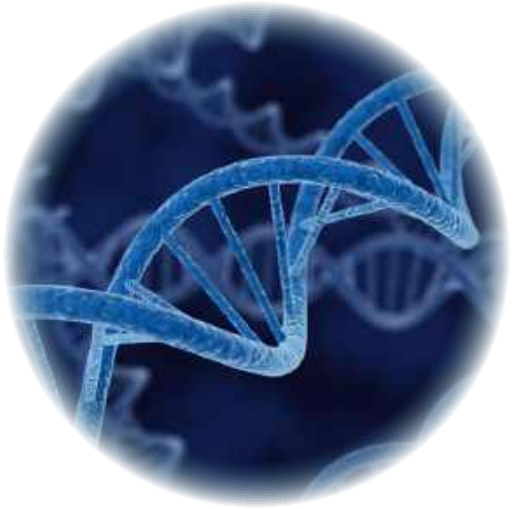
Technology



Paul

The patient challenge

PATIENT EXPERT CENTER



Biology



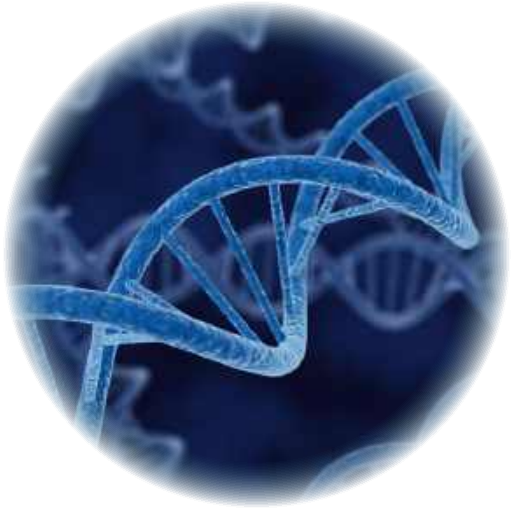
Technology



Tracy

The patient challenge

PATIENT EXPERT CENTER



Biology



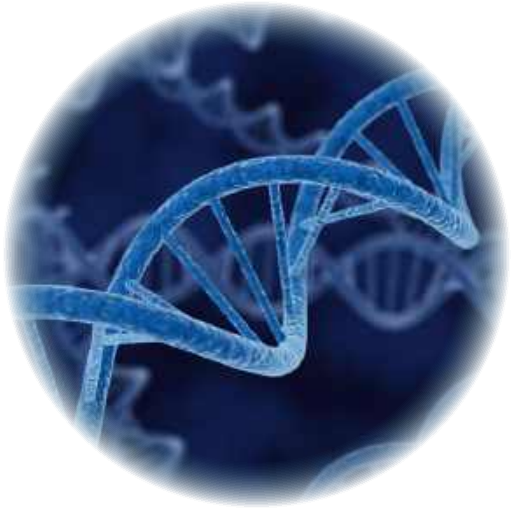
Technology



Bert

The patient challenge

PATIENT EXPERT CENTER







Biology **Technology** **Cathy**

Medical Community

Patient Community

The patient challenge



Who says I have only a biological issue?

The patient challenge

PATIENT EXPERT CENTER

Life Goals

Medical treatment

Medical support

Understanding

Comorbidities

Support services

Revalidation

Bureaucracy

Practical aspects

...



Relationship

Family

Social life

Work/Studies

Self-image & Mental health

Free time and hobbies

Financial aspects

Insurance

Technology works optimally when correctly embedded into Cathy's world

PATIENT EXPERT CENTER

Life Goals

Medical treatment

Medical support

Understanding

Comorbidities

Support services

Revalidation

Bureaucracy

Practical aspects

...



Relationship

Family

Social life

Work/Studies

Self-image & Mental health

Free time and hobbies

Financial aspects

Insurance

LIVING WITH A DISEASE

It's more than what you see

A daily, ongoing journey that touches every part of life. Not always easy, but you're not alone—and support exists.



MEDICAL & HEALTH

Medical Services

- Diagnosis & tests
- Appointments
- Medications
- Procedures
- Monitoring
- Managing side effects
- Hospital care
- Preventive care



Extramural Support Services

- Physiotherapy
- Psychology / Counselling
- Dietitian / Nutrition
- Occupational therapy
- Social work / Case management
- Complementary therapies
- Speech therapy
- Exercise programs
- Patient associations

Symptoms & Fluctuations

- Pain
- Fatigue
- Flare-ups
- Unpredictability

Impact on Body

- Energy
- Mobility
- Sleep
- Appetite
- And more

Treatment & Management

- Medications
- Procedures
- Lifestyle adjustments
- Tracking & monitoring
- Trial & error

Daily Management

- Routines
- Planning
- Self-advocacy
- Knowing your body



Healthcare System Navigation

Appointments | Referrals | Insurance | Costs | Waiting times | Being heard

SOCIAL & RELATIONSHIPS

Understanding (or lack of it)

- "You don't look sick"
- Misunderstood
- Judged



Support System

- Family
- Friends
- Communities
- Online support



Changing Dynamics

- Relationships shift
- Hard conversations
- Asking for help



Balancing Act

- Don't want to burden others
- Guilt
- Setting boundaries



WORK / SCHOOL

- Keeping up
- Asking for accommodations
- Brain fog
- Career impact
- Calling out
- Proving yourself



FINANCIAL IMPACT

- Medical bills
- Insurance
- Reduced income
- Extra costs
- Financial stress



DAY-TO-DAY LIFE

Good days	Bad days	Plan	Cancel	Rest	Celebrate
Savor them	Survive them	Adjust constantly	without guilt	Not laziness, necessity	Small wins

IDENTITY & MEANING

- Grieving the old you
- Redefining success
- Finding new purpose
- Holding on to hope



COPING & SELF-COMPASSION



THIS IS NOT A LINEAR JOURNEY — THERE WILL BE UPS & DOWNS

LOOKING AHEAD

- Hope
- Resilience
- Acceptance
- Growth

One day at a time



WHAT I WANT YOU TO KNOW

- I may not always have the words.
- I may need rest, not advice.
- Your patience means more than you know.
- I'm still me. I'm doing my best.

THANK YOU FOR SEEING ME.

EVERY PERSON. | EVERY DISEASE. | EVERY JOURNEY IS UNIQUE. | COMPASSION. | AWARENESS. | EMPATHY. | TOGETHER, WE CAN LIGHTEN THE LOAD.

Integrating two worlds

PATIENT EXPERT CENTER

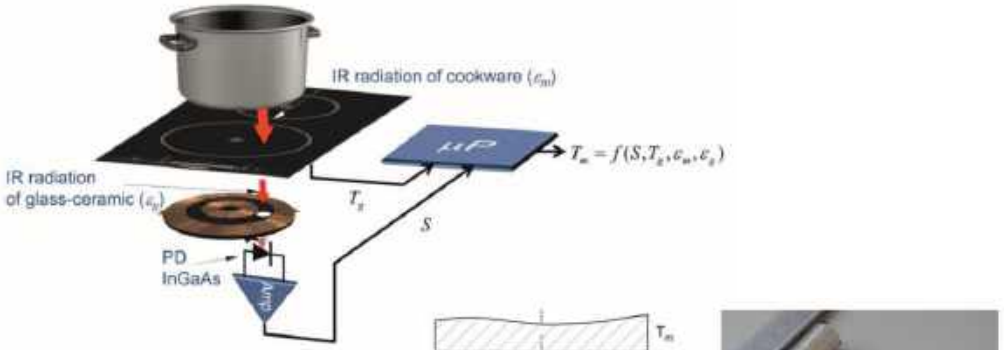
- Predictable
- Control
- Scalable
- Quality guarantees
- Approval
- Precision
- Evidence

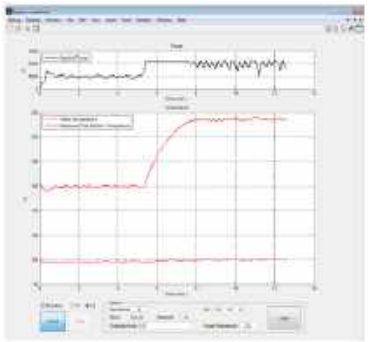
- Unpredictable
- No control
- Unique
- Undisciplined
- Random
- Erroneous
- Emotions

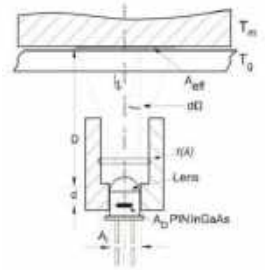
Anticipation + Support = Success

Who knows more about cooking?

PATIENT EXPERT CENTER









The four contributions to $E_\perp(\lambda, T_g, T_m)$ can be expressed as:

$$E_{\perp,1}(\lambda, T_m) = T\varepsilon_m \frac{E_{BB}(\lambda, T_m)}{\pi} d\Omega$$

$$E_{\perp,2}(\lambda, T_g) = \varepsilon_g(\lambda) \frac{E_{BB}(\lambda, T_g)}{\pi} d\Omega$$

$$E_{\perp,3}(\lambda, T_m) = T\varepsilon_m \frac{E_{BB}(\lambda, T_m)}{\pi} \frac{R(1-\varepsilon_m)}{1-R(1-\varepsilon_m)} d\Omega$$

$$E_{\perp,4}(\lambda, T_g) = \varepsilon_g(\lambda) \frac{E_{BB}(\lambda, T_g)}{\pi} \frac{T(1-\varepsilon_m)}{1-R(1-\varepsilon_m)} d\Omega$$

Javier Lasobras et al.: Infrared Sensor-Based Temperature Control for Domestic Induction Cooktops, in *Sensors*, 2014

A



B

Both the scientific and experience perspective are essential for optimal care

PATIENT EXPERT CENTER

The MDT knows more ....



.... about the clinical aspects

Patient associations know more ....



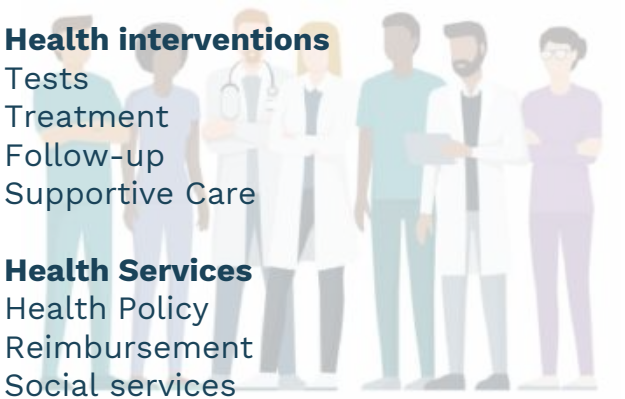
.... about living with the disease

.... about the patient pathway

Zoom in on Organised Care

PATIENT EXPERT CENTER

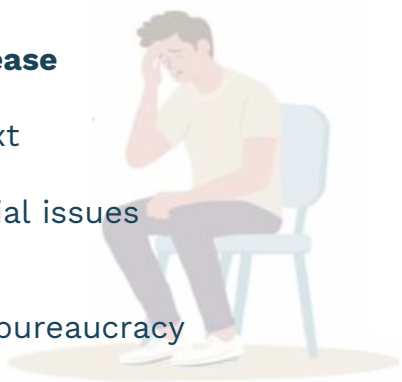
ORGANISED CARE



Health interventions
Tests
Treatment
Follow-up
Supportive Care

Health Services
Health Policy
Reimbursement
Social services

SELF-RELIANT PATIENT



Living with disease
Life goals
Personal context
Comorbidities
Mental and social issues
Practical needs
Health literacy
Administrative bureaucracy
Navigation

Zoom in on Organised Care

PATIENT EXPERT CENTER

ORGANISED CARE

Health interventions
Tests
Treatment
Follow-up
Supportive Care

Health Services
Health Policy
Reimbursement
Social services

Human mistakes

~~SELF-RELIANT PATIENT~~

Living with disease
Life goals
Personal context
Comorbidities
Mental and social issues
Practical needs
Health literacy
Administrative bureaucracy
Navigation

Human mistakes



Zoom in on Organised Care

PATIENT EXPERT CENTER

ORGANISED CARE



Health interventions
Tests
Treatment
Follow-up
Supportive Care

Health Services
Health Policy
Reimbursement
Social services

SELF-RELIANT PATIENT



Living with disease
Life goals
Personal context
Comorbidities
Mental and social issues
Practical needs
Health literacy
Administrative bureaucracy
Navigation

PATIENT COMMUNITY

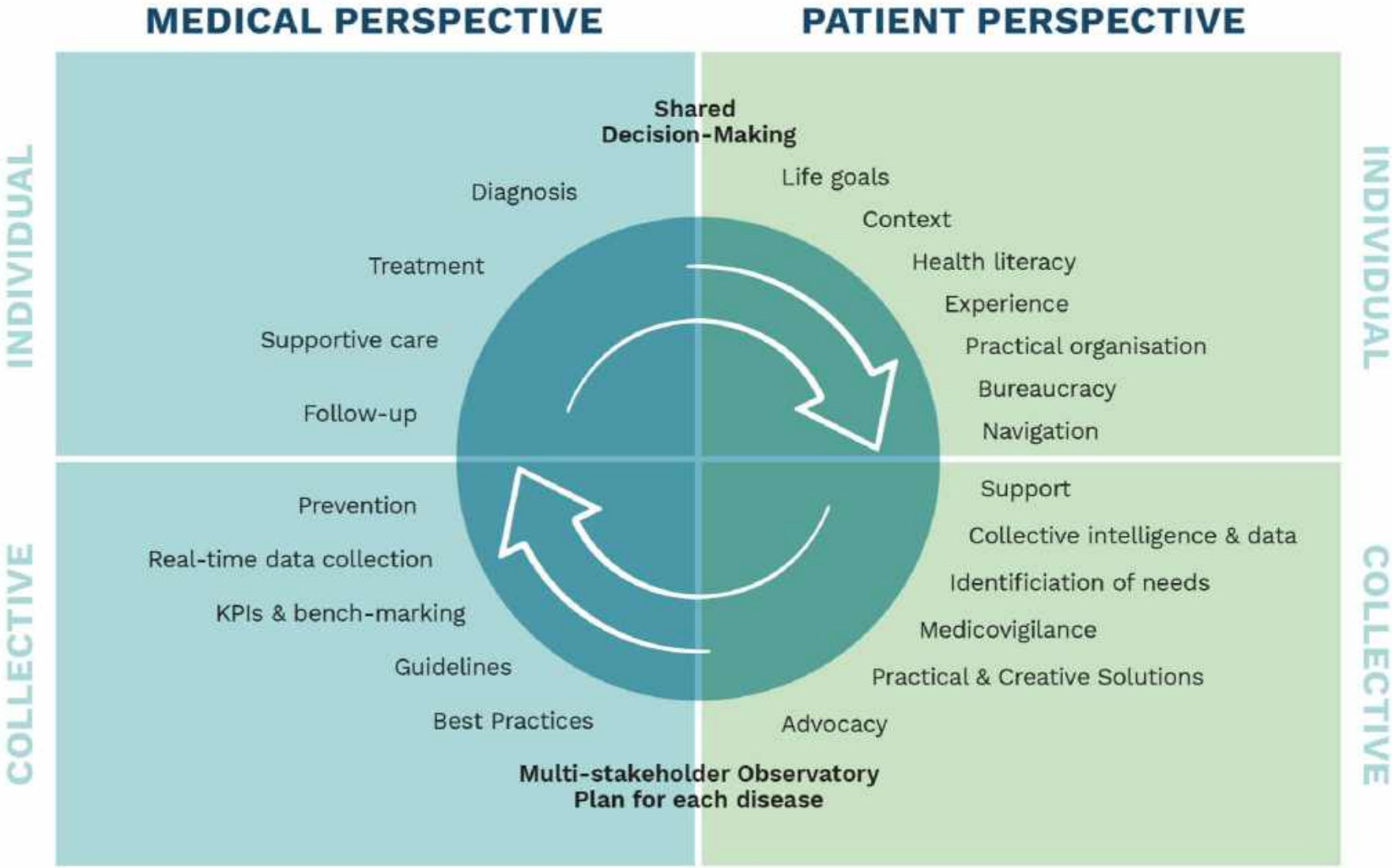


Patient Community Feedback
Collective intelligence & surveys
Value determination
Identification of needs and expactations
Health economic analyses
Collaborative efforts to improve care
Creative solutions

Patient Support
Information & education
Preparing consultations
Practical solutions
Self-esteem and self-development
Coping strategies
Motivation
Community support
Volunteer work & home visits

Optimal care thanks to the full integration of the medical and patient perspective

PATIENT EXPERT CENTER



PATIENT EXPERT CENTER

The patient pathway

Supportive Care

Medical

Me

My World



Best Possible Outcomes

Patient engagement across medtech innovation

Potential interactions from discovery to market access

PATIENT EXPERT CENTER

Discovery	Concept & design	Evidence planning	Clinical evaluation	Regulatory review	Market access
Understand unmet needs	**Co-create the solution**	**Shape meaningful studies**	**Improve study experience**	**Inform benefit–risk review**	**Demonstrate patient value**
Lived-experience interviews	Concept and prototype co-design	Outcomes and endpoint selection	Study advisory groups	Experience and preference data	Early HTA and payer dialogue
Patient journey mapping	Usability and accessibility tests	Patient-reported measures	Participant support and feedback	Patient input in regulator dialogue	Patient input in HTA appraisals
Research priority workshops	Device and service requirements	Preference study co-design	Quality of life and experience	Testimony and advisory input	Caregiver and economic burden
Patient and caregiver listening	Privacy and data-use preferences	Protocol and consent review	Use validation and training tests	Labeling and information review	Affordability and access barriers
Benefit–risk and burden insights	Instructions and training review	Recruitment and inclusion plans	Results and lay summaries	Explain evidence gaps	Training and decision aids
Patient-defined needs	**Patient-informed design**	**Relevant, feasible studies**	**Evidence that matters**	**Patient context for review**	**Access and adoption insight**

CONTINUOUS PARTNERSHIP Patient and caregiver advisory groups / Inclusive participation / Fair compensation / Accessible communication / Feedback on impact

Access planning starts early. Post-launch experience, registries and safety feedback inform evidence generation and the next design cycle.

Our practical services and tools

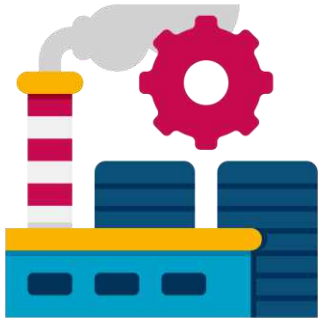
PATIENT EXPERT CENTER

Care Pathways
Quality of Care
Governance
Exit Interviews



Hospital

Patient Pathway
Patient Information
Clinical research



Industry

Real World Evidence
Issues Management
Health Economic Analysis

Awareness Campaigns
Disease dashboards
Patient-Centric Culture
Formal Collaboration Models
Training

Prevention
Health Policy Plan
Research Priorisation
Patient Surveys
Patient Engagement



Government agencies



Individual treatment

Checklist
Patient Bio
Info kit
Chatbot
Standard questions
Shared Decision-making
Decision Aids
Patient-friendly letter
Data access
Contact card
Volunteer support

Systematic integration of patient experience in patient pathway

PATIENT EXPERT CENTER

- Mapping the patient pathway
  - high level inventory of clinical and non-clinical interventions and experiences
  - metromapping

- A plan for every disease
  - co-determination of key performance indicators
  - co-determine priorities and act on them
  - evaluation and adaption



Our services and tools

PATIENT EXPERT CENTER



Post-diagnosis Checklist



Information Kit



Shared Decision-Making Model



Patient Activation



Patient Bio



Chatbot



Decision Aids



Patient Roadmap



Contact Card



Standard List of Questions

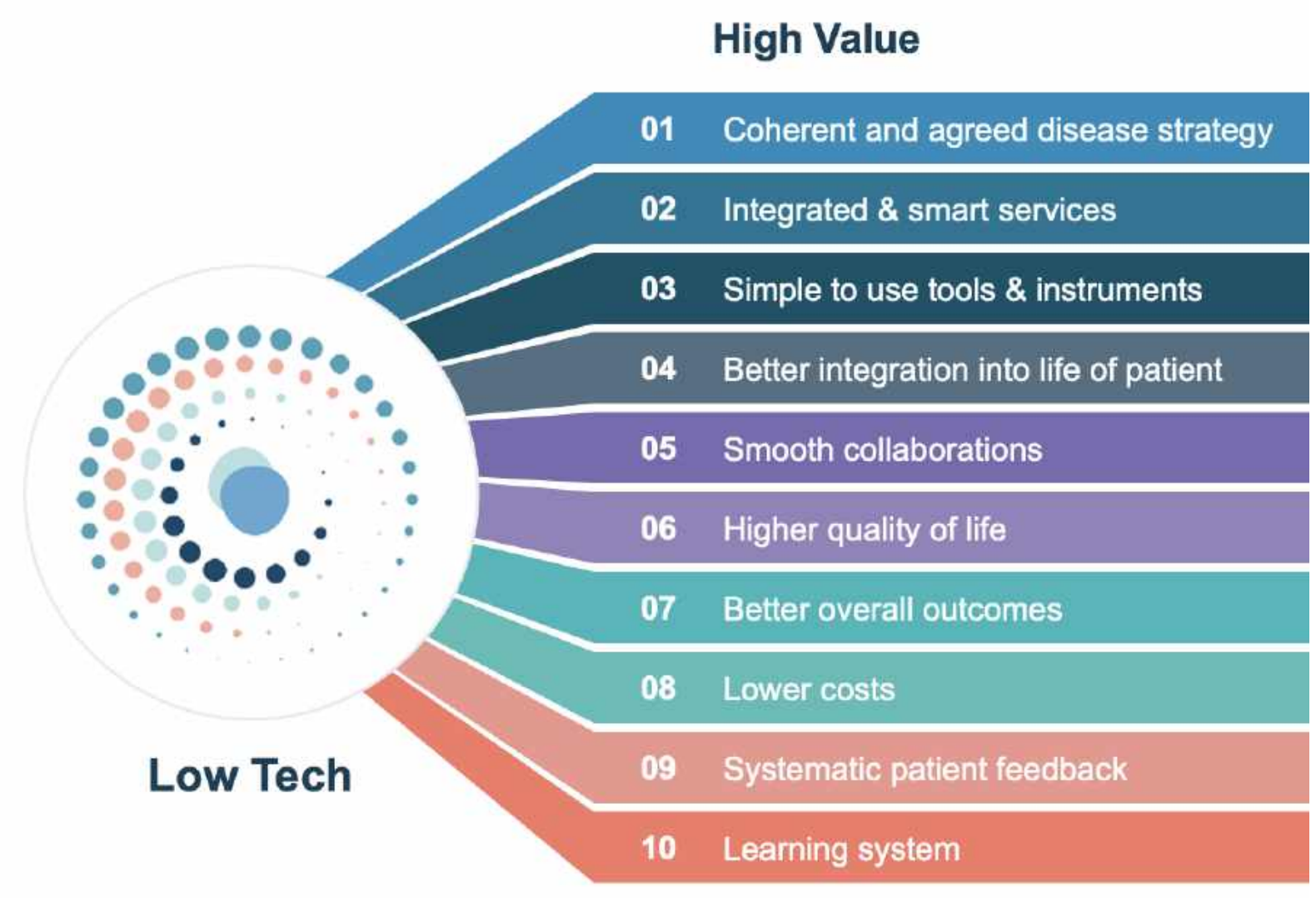


Patient-friendly Treatment Plan



Patient-friendly Letter

PATIENT EXPERT CENTER



We find solutions for medical problems



Medical world

We help patients to be themselves despite their medical problem



Patient Organisations

Thank you for working with us!

PATIENT EXPERT CENTER

