

**Building a Smarter Health and Wellness Future
OECD/NSF Washington 2011**

**Citizens Centered Health
Information:
A view from Portugal**

**Constantino Sakellarides
February, 2011**

Health and digital literacy workshop - Diabetes association of Barreiro, Portugal



Personal health information systems: Portuguese experience I

A SMALL SCALE EXPERIMENT

(2007-2009)

With a personal health information system

Diabetics Association in Barreiro (a town, across the Tagus river from Lisbon) with approximately 1050 members

- 500 active ones
- 50 participated in the experiment (age 40 to 80; low socioeconomic condition)



National School
of Public Health



DGS
Ministry of
Health

A SMALL SCALE EXPERIMENT

The screenshot displays the 'i-citizen Personal Health Information System' interface. At the top, there is a navigation menu with options like 'Informação Pessoal', 'Sinais Vitais', 'Problemas de Saúde', and 'Meus Documentos'. The main content area is titled 'Tensão Arterial' (Blood Pressure). It includes a description: 'A tensão arterial é a resposta da pressão exercida pelo sangue nas paredes das artérias quando bombeado pelo coração.' Below this is a calendar for September 2007, with the 1st highlighted. There are input fields for 'Data de Medição', 'Hora de Medição', 'Sistólica (Máxima)', and 'Diastólica (Mínima)'. A table below shows recorded blood pressure readings:

Código	Data	Hora	Valor	Nome
127	2007-09-26	20:13:00	100,000	Diastólica (Mínima) - Apreciar
128	2007-09-26	20:13:00	140,000	Sistólica (Máxima) - Apreciar
129	2007-09-26	20:11:00	120,000	Diastólica (Mínima) - Apreciar
134	2007-09-26	20:11:00	160,000	Sistólica (Máxima) - Apreciar
131	2007-09-26	18:28:00	120,000	Diastólica (Mínima) - Apreciar
130	2007-09-26	18:28:00	140,000	Sistólica (Máxima) - Apreciar

Below the table is a line graph showing the blood pressure trend over time. The y-axis represents pressure values from 0 to 184. The x-axis shows the date 2007-09-26. The graph shows two data points for each time slot, with the highest value (160) highlighted.

Motor de busca
www.google.pt
correio electrónico
www.gmail.com

Joint development and
evaluation of PHR prototype

Personal health information systems: Portuguese experience I

1.

We can do it!
... useful way to organize
personal health information

3.

... how to fit it in our daily
living?

2.

... can inputting be simplified?

4.

... currently outside
mainstream thinking
in health services

2009 evaluation

From a small scale experiment
To a large scale implementation and evaluation program
A partnership between Portuguese Telecom (PT) and the N School of PH



Portugal Telecom



Escola Nacional de Saúde Pública
Universidade Nova de Lisboa

MEU Sapo Saúde

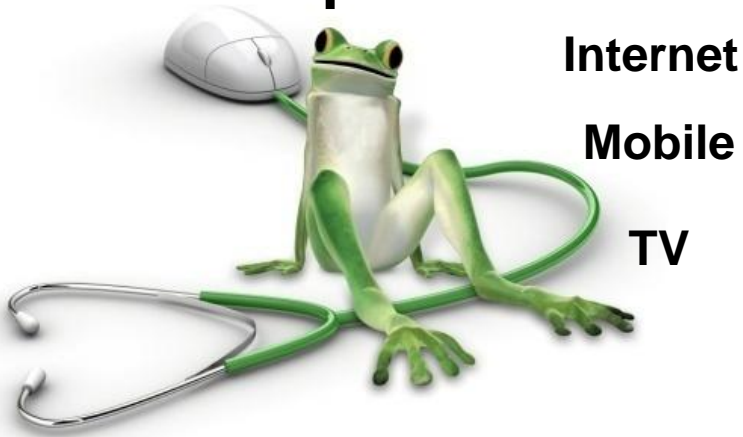
Personal Health Information System



Personal Health Information Systems

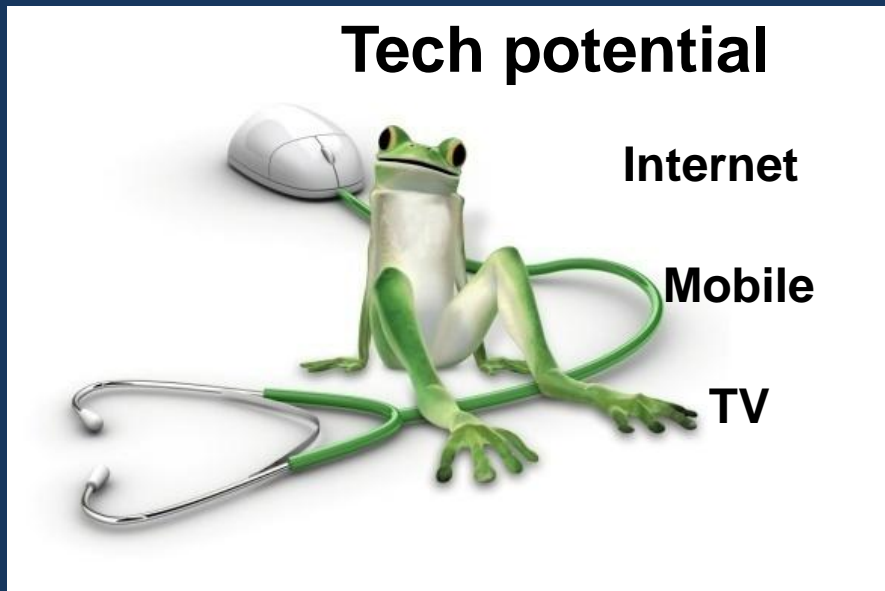
MEU. SAPO.SAÚDE

Tech potential



Personal Health Information Systems

MEU. SAPO.SAÚDE



Expanding/promoting utilization – next step

PT h. services = 100.000

NHS phc = 100.000

Diabetes Ass = 1.000

Personal health information systems: **main objectives**

EMPOWERMENT

Repositioning citizens in the health system

HEALTH LITERACY

Using information intelligently
in day-to-day health related decisions

COMMUNICATION

Interacting with others

INFORMATION MANAGEMENT

Capturing, annotating, storing and
processing data and information

INFORMATION and HEALTH PROTECTION

Ensuring readability and information transfer

Adapted from: Sakellarides, C, Pedro, AR, Mendes, MS. Knowledge-centered health innovation -
The case for citizen health information systems, 2009



FUNDAÇÃO



PT Prime

Promoting health literacy through Personal health information systems

Development strategy in “unprepared”
environment: 8 complementary approaches?



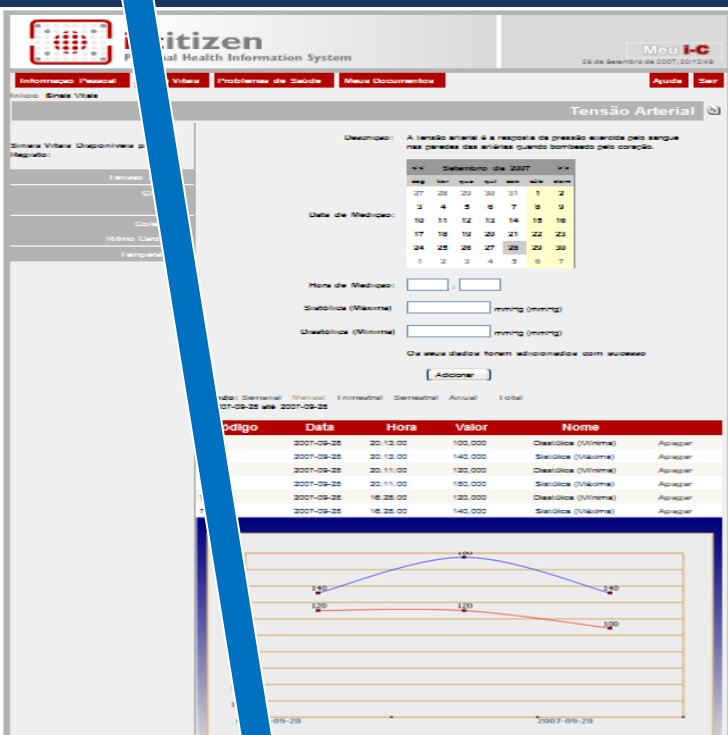
1. Linking with EHR

Electronic health records across all NHS services

2009-2012 project

Citizen centered information

Professional managed information



Early pilot proposed

Personal health information system
Citizen centered and managed health information

Personal health information systems structure

Personal and family health

Self – recording

Self - measurement

Self – management

Health care

Import/export health care information

Information exchange with health care providers, caregivers, family

Support systems

1. Linking with EHR

Opportunity: makes sense – right timing

Limitations: hierarchical view: providers first

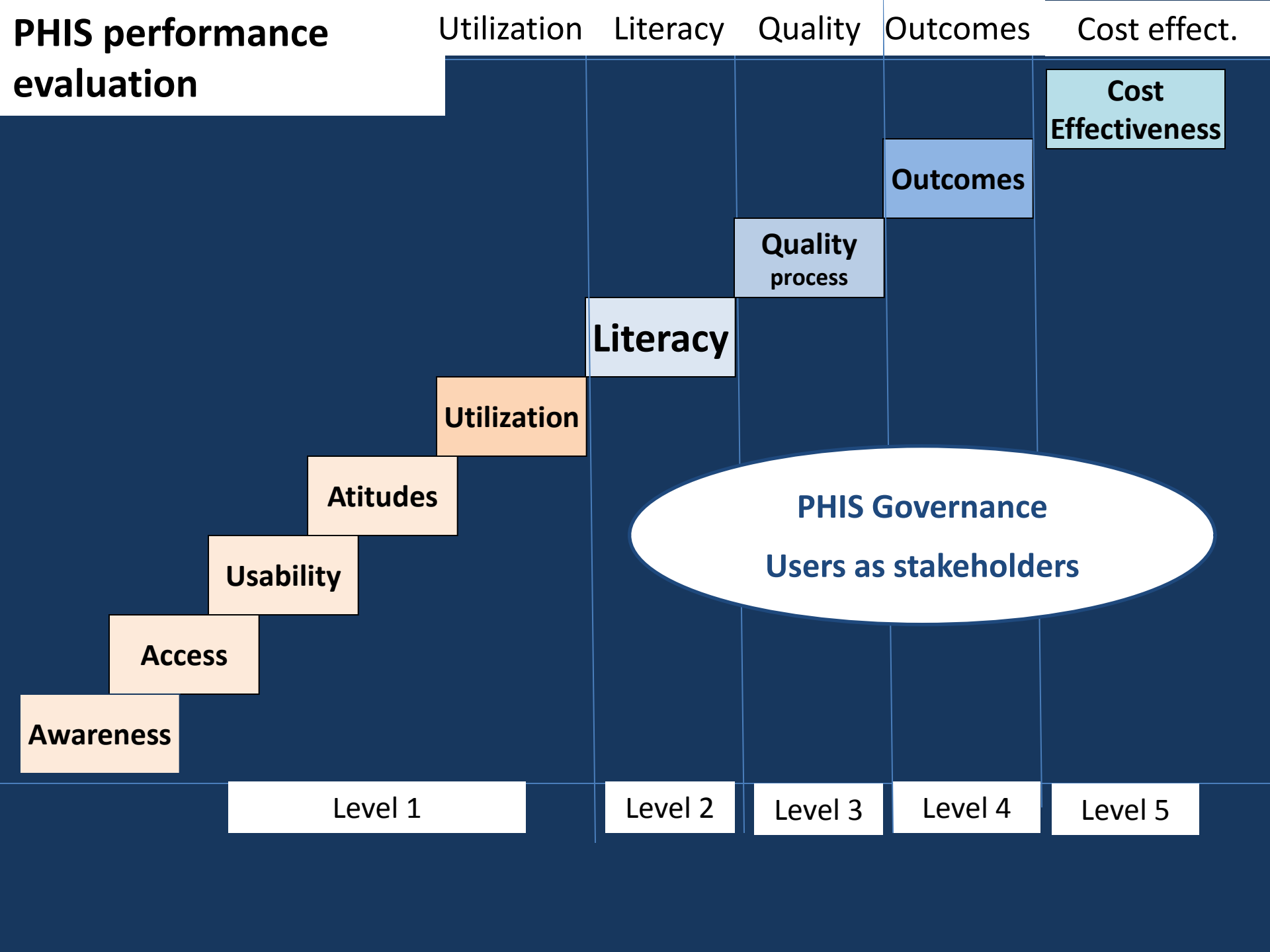
2. Knowledge support and evaluative research

Electronic health records
Citizen centered information
Professional managed information

Knowledge support systems
Knowledge translation and dissemination

Código	Data	Hora	Valor	Nome	Aprovar
T97	2007-09-26	20:13:00	100,000	Diastólica (Mínima)	Aprovar
T98	2007-09-26	20:13:00	140,000	Sistólica (Máxima)	Aprovar
T99	2007-09-26	20:11:00	120,000	Diastólica (Mínima)	Aprovar
T94	2007-09-26	20:11:00	180,000	Sistólica (Máxima)	Aprovar
T91	2007-09-26	18:28:00	120,000	Diastólica (Mínima)	Aprovar
T90	2007-09-26	18:28:00	140,000	Sistólica (Máxima)	Aprovar

Personal health information system
Citizen centered and managed health information



2. Knowledge support and evaluative research

Opportunity: need recognized

Limitations: too many

opportunistic impulses – funding difficulties

3. Participatory innovation and shared ownership

Electronic health records
Citizen centered information
Professional managed information



Knowledge support systems
Knowledge translation and dissemination

Código	Data	Hora	Valor	Nome	Aprovar
T97	2007-09-28	20:13:00	100,000	Diastólica (Mínima)	Aprovar
T98	2007-09-28	20:13:00	140,000	Sistólica (Máxima)	Aprovar
T99	2007-09-28	20:11:00	120,000	Diastólica (Mínima)	Aprovar
T94	2007-09-28	20:11:00	180,000	Sistólica (Máxima)	Aprovar
T91	2007-09-28	18:28:00	120,000	Diastólica (Mínima)	Aprovar
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Personal health information system
Citizen centered and managed health information



Social networks
Web 2.0

3. Participatory innovation and shared ownership

Opportunity: broaden social base

Limitation: corporate culture not yet attuned

4. Emphasis on customization ... **starting with the patient**

2. Information export/import communication capacities

1. Basic Module (display, reminder systems)

Basic problem list

Selected health monitoring: weight, blood pressure, and others

Diagnostic tests results (Eye and dental records)

Medicines in use; immunization

Allergies and other emergency information (break-the-glass rules)

3.1 Organize personally relevant information
Health services navigation

3.2 organize personally relevant information
Social, behavioral, environ. health determinants

3.3 Organize personally relevant information
Biomedical determinants

2. Information export/import communication capacities

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9. Personal health management

Advanced problem list
Personal health and
health care program

8. Personal health statements

Living will and advanced orientations;
Organ donation authorization;
Permission, consent forms

6. Choice and voice opportunities

7. Health risk profile

4. Financing and payment information: Regular mandatory contribution
Private insurance; Direct payments

3.1 Organize personally
relevant information
**Health services
navigation**

3.2 organize personally
relevant information
**Social, behavioral, environ.
health determinants**

3.3 Organize personally
relevant information
**Biomedical
determinants**

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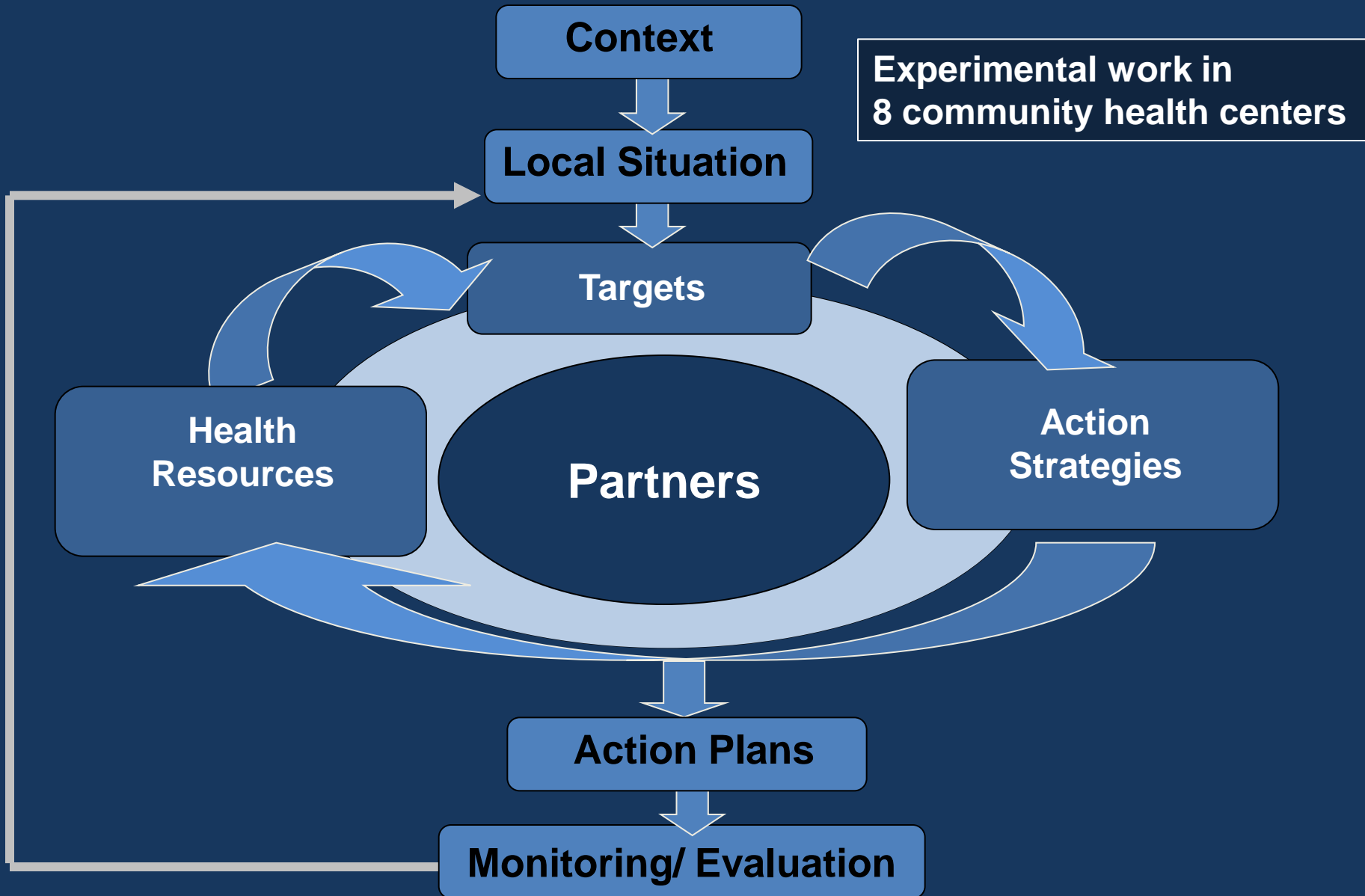
4. Emphasis on customization

Opportunity: adaptation to complexity and personalized health information

Limitation: not seen as an “early” issue

5. Community and public health support

Local Health Strategies



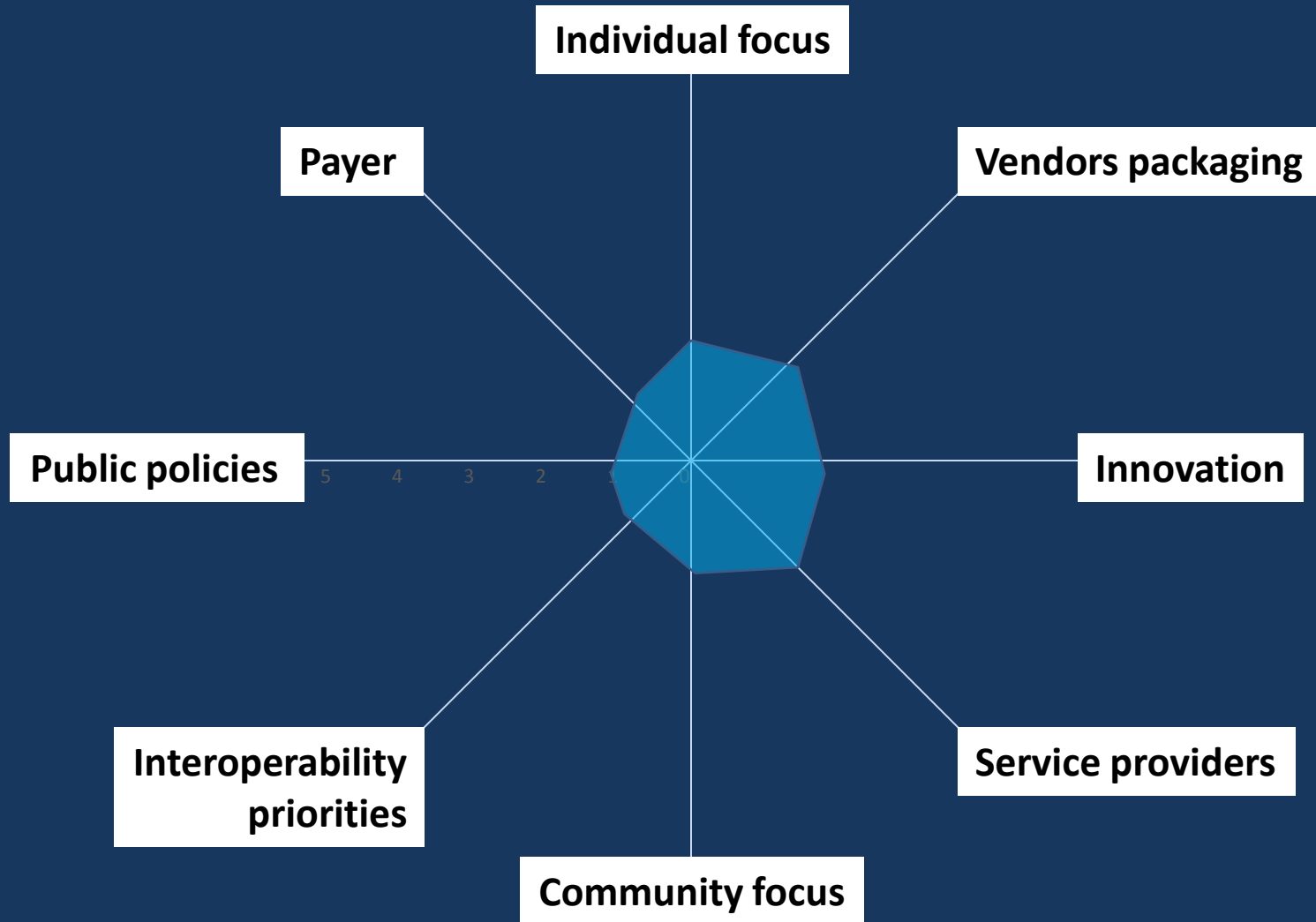
5. Community and public health support

Opportunity: broad community involvement – focus on outcomes, local partnerships and communication strategies

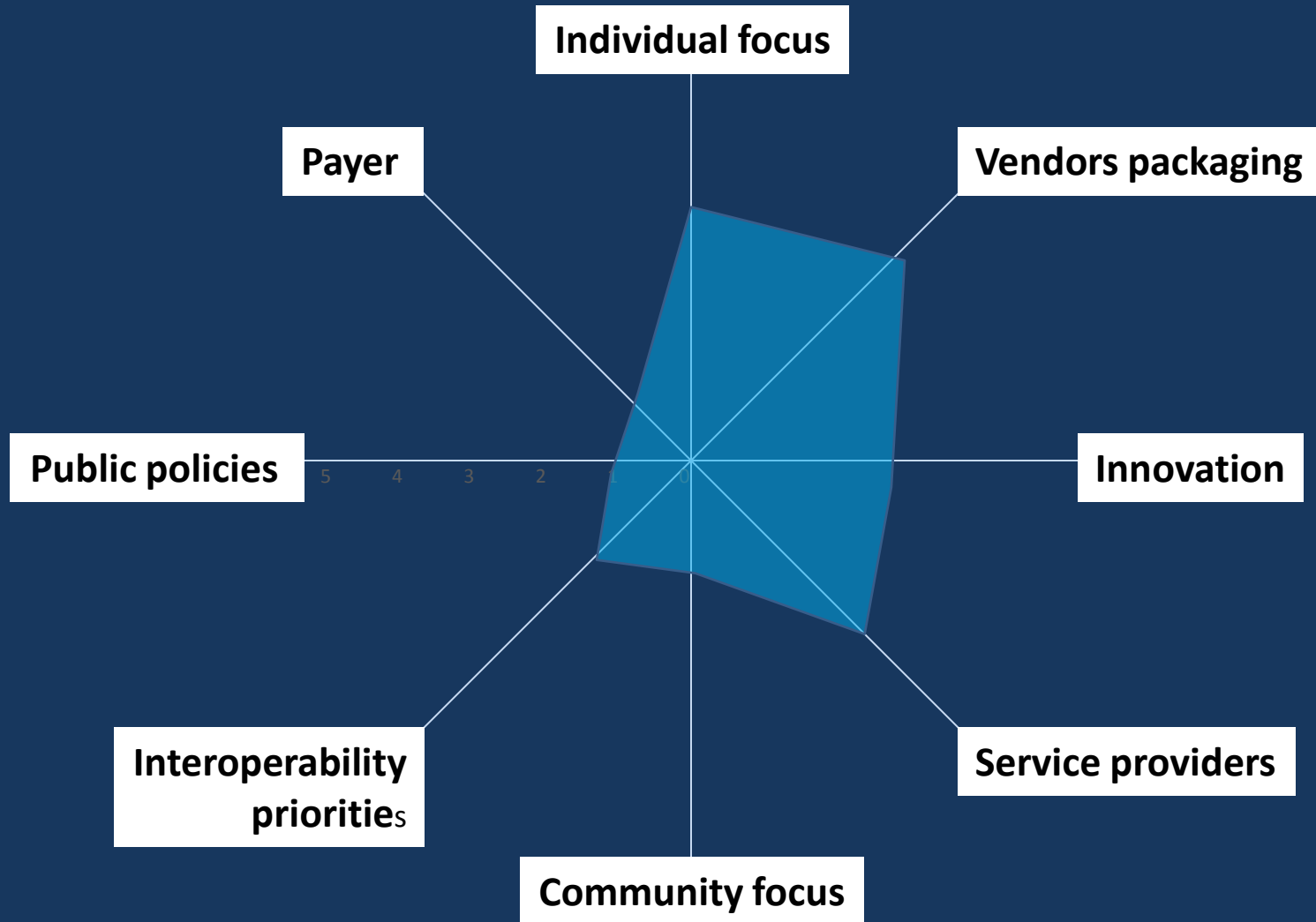
Limitations: early development stage

6. Health information governance

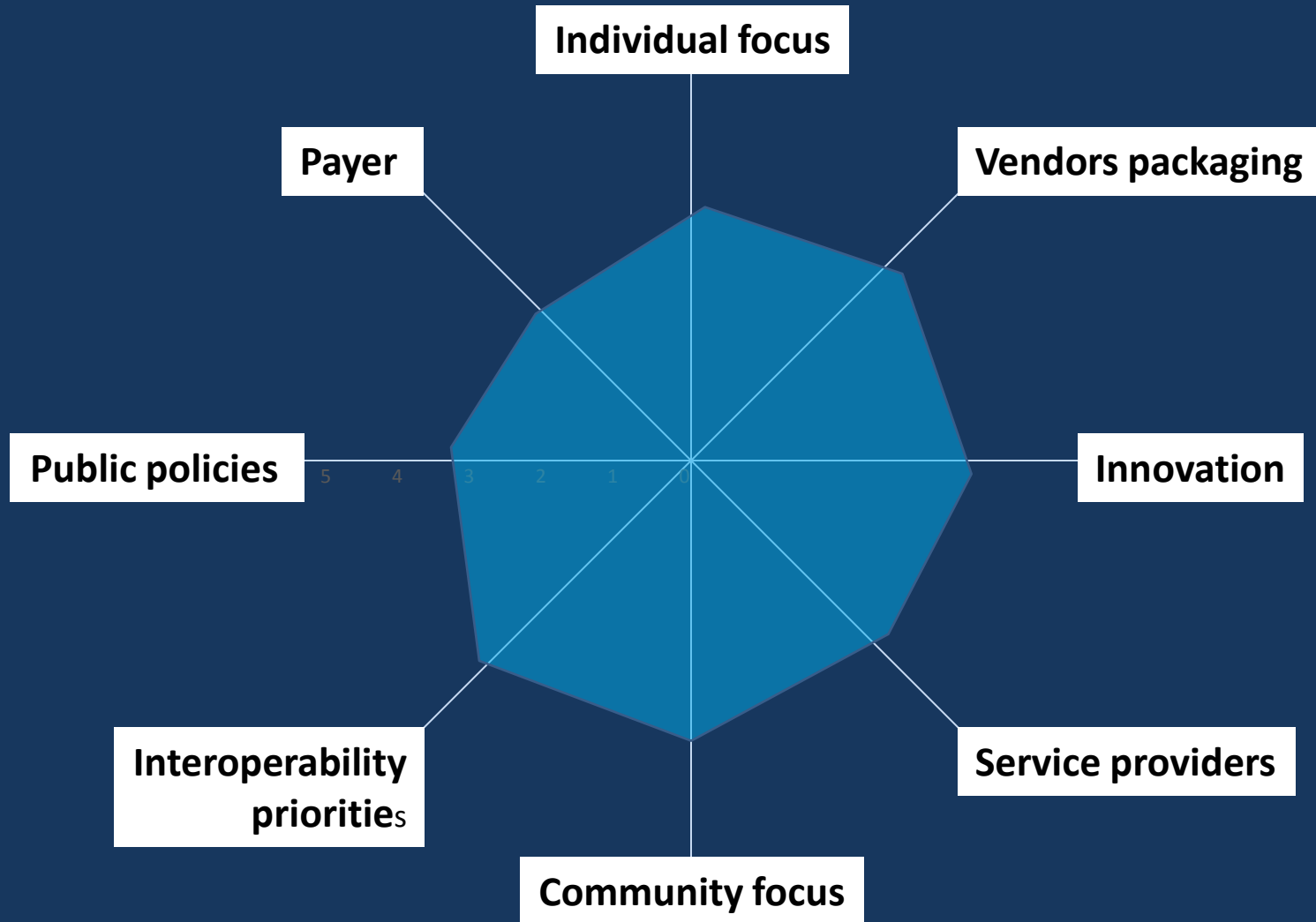
Governance: Defensive scenario



Governance: Unbalanced development scenario



Governance: Balanced development scenario



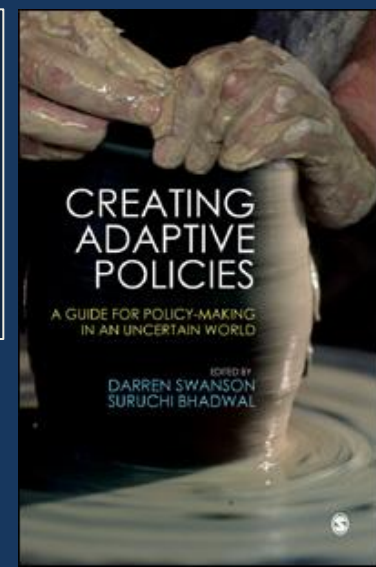
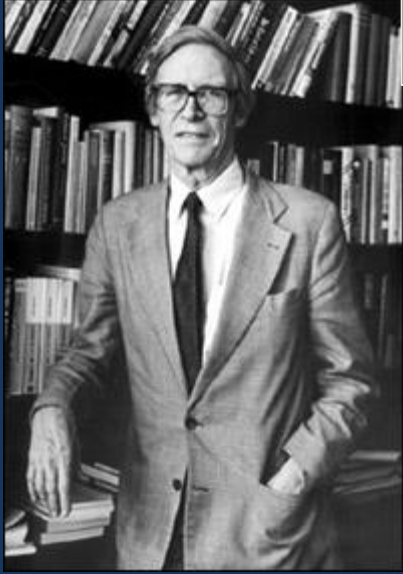
6. Health information governance

Opportunity: need of an overview

Limitation: no clear locus for
governance debate

7. New “social contract”

Health literacy and empowerment as critical elements of a **new social contract for health** Systems and micro level



Institutionalism

John Rawls **Theory of Justice** (1971)

“The justification and prescription of perfectly just institutions”

Engaged deliberative incrementalism

Amartya Sen **The Idea of Justice** 2009

Dynamic “agreements based on public reasoning on ranking alternatives that can be realized”



7. New “social contract”

Opportunity: intellectual challenge
for a crises period

Limitations: small constituency too
close to “politics”

8. International cooperation

The NEW ENGLAND JOURNAL of MEDICINE 2008

Tectonic Shifts in the Health Information Economy

Mandl, K, Kohane, I.

Join the Boston CH, Harvard, MIT
INDIVO family

8. International cooperation

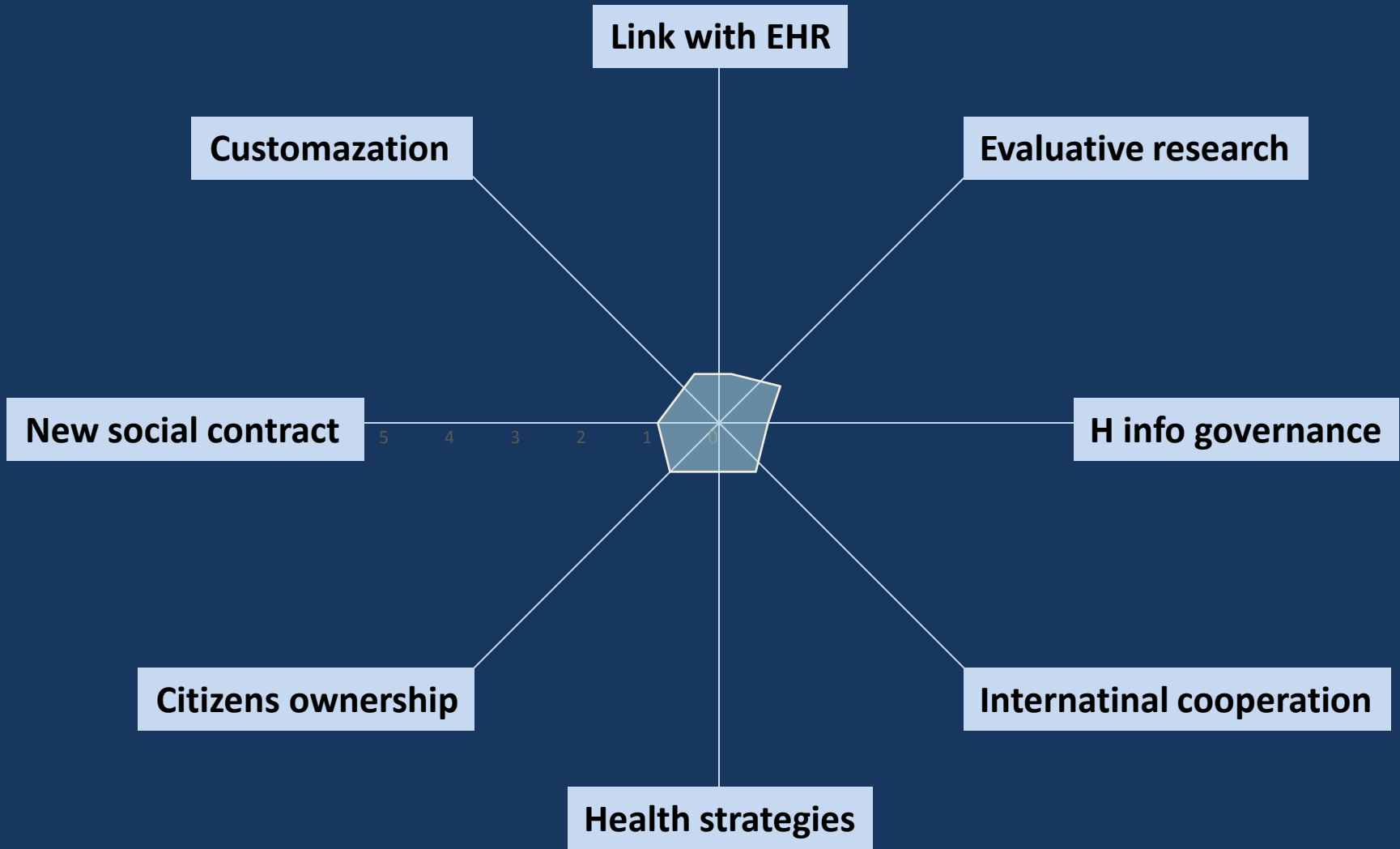
Opportunity: Learn, adapt, exchange

Limitations: ...“too soon for us”

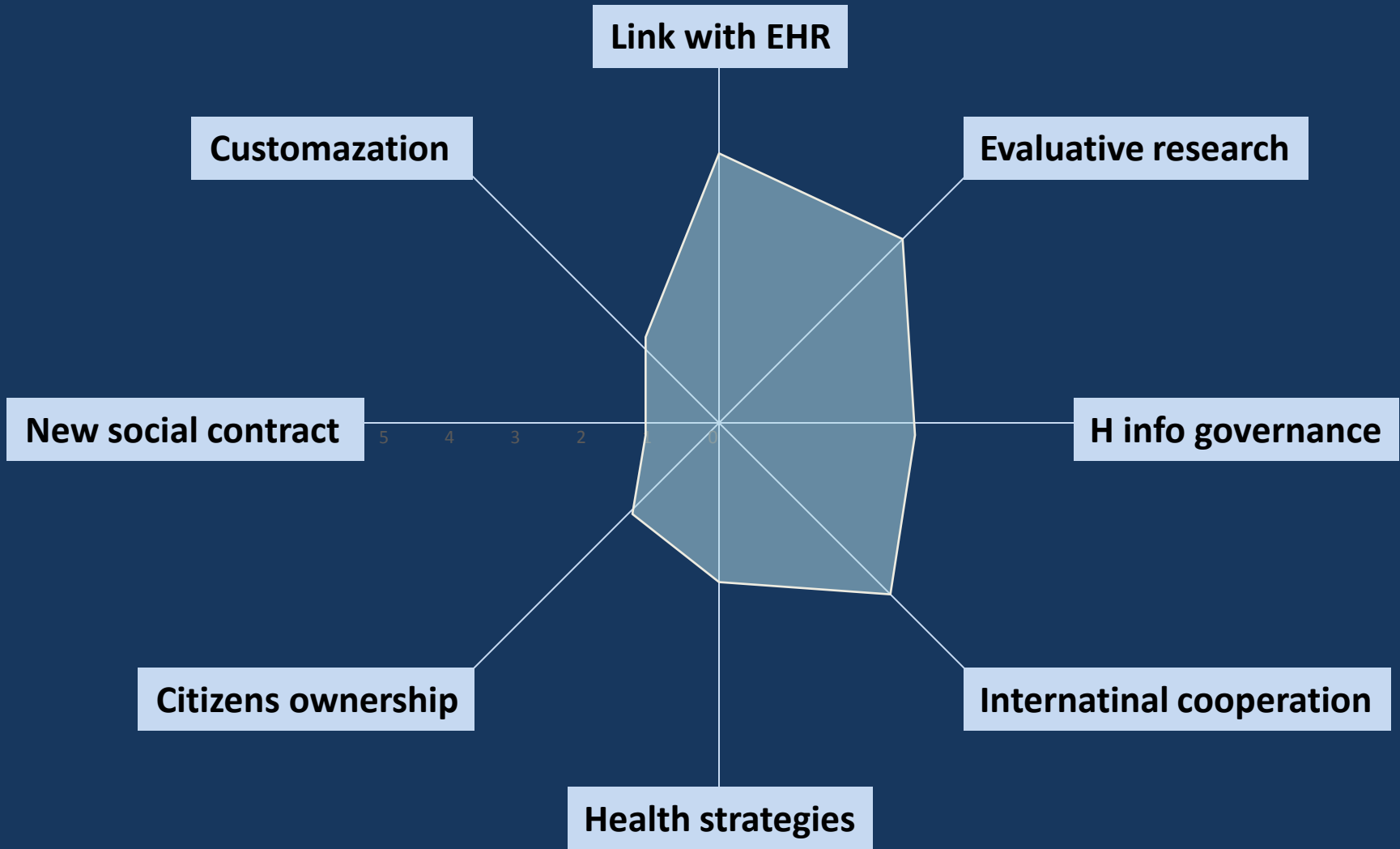
**Promoting health literacy
through
Personal health information systems**

Development strategy – a summary

Promoting health literacy through Personal health information systems - Next step ?



Promoting health literacy through Personal health information systems - Next steps ?





... maybe the issue is not

how much a hostile place the world is

but rather that we are not just SMART
ENOUGH (yet) to face these challenges!

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