

# PROVISION PILLAR

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# WHAT

Which kind of genomic technology and genomic information can be transferred from the research setting to the system of health care and public health services.

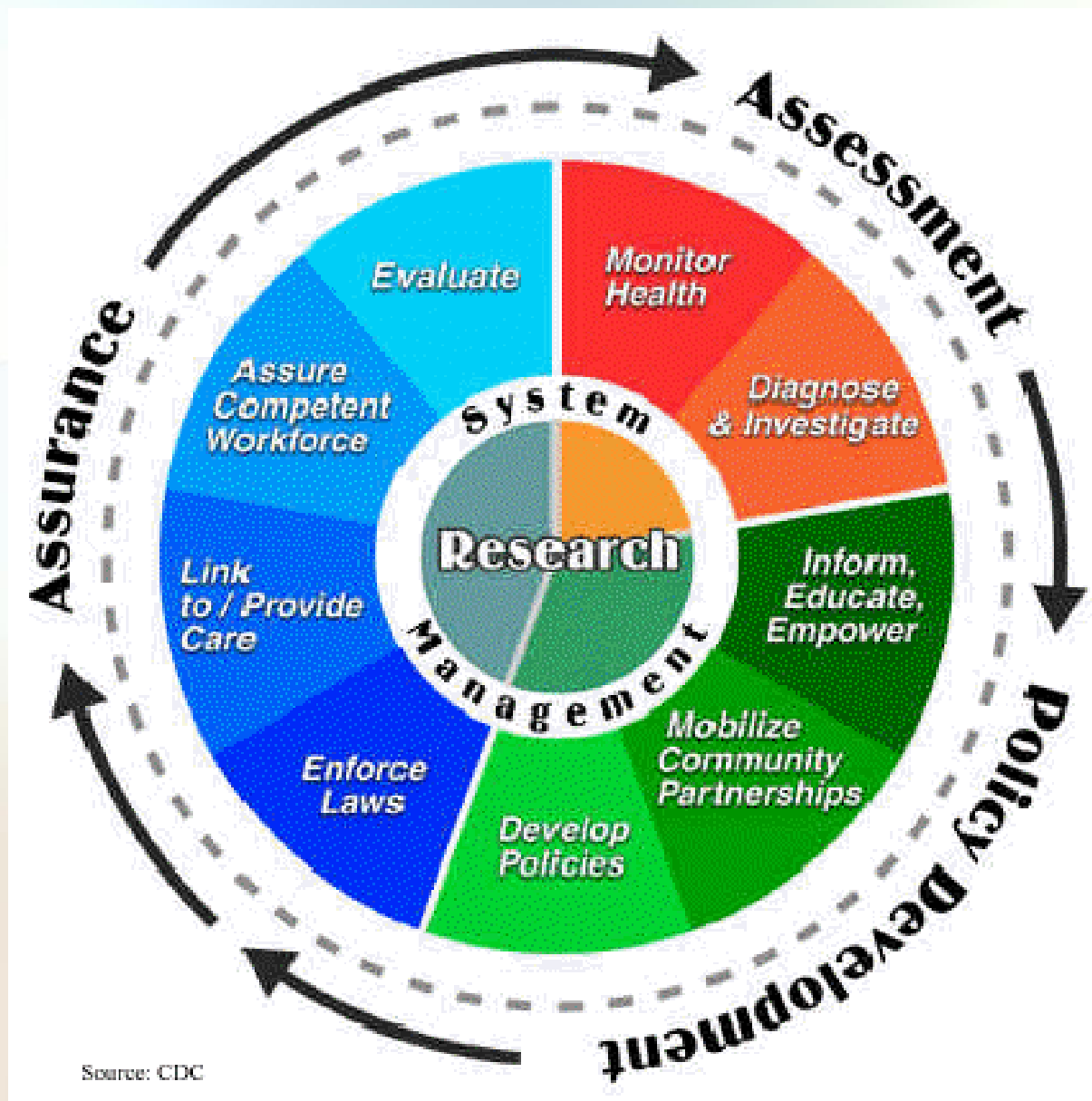
# HOW

In order to introduce the genome-based information into Public Health it's important

- to validate technology in the diagnostic setting (HTA-Health Technology Assessment) and
- to establish a clear relationship between genomic information and contemporary methods of translation of medical research.

# IN WHAT WAY

- to define how to supply a good communication, the training requirements and competencies for the professionals to be involved in public health genomics-based interventions and technologies
- to help decision makers to understand the genomic implications in decision making processes and to choose the “right health services for the right groups of patients and subpopulations”
- to provide guidelines for decision makers



Source: CDC

# ASSESSMENT

Monitor Health

Diagnose & Investigate

# Monitor Health

What and how should be done for quality and successful monitoring of population health?

1. Professional Ethics

2. ELSI

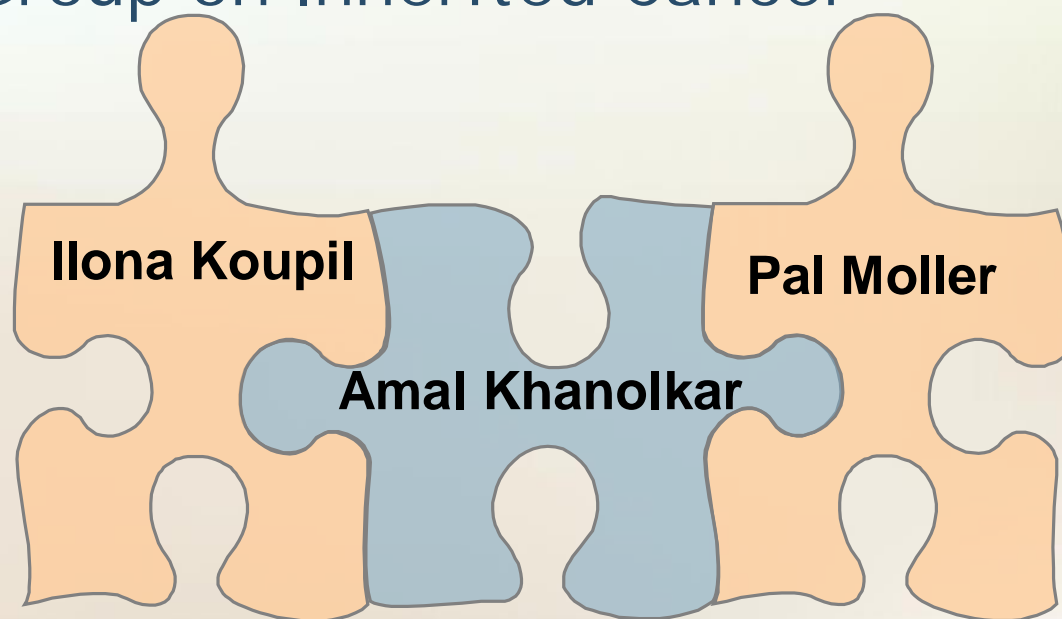
[http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/elsi.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml)

3. Overview of health monitoring and health priority setting systems

4. ICD 11 considerations

# Institute/persons to be responsible

- Centre for Health Equity Studies (CHESS)  
Stockholm University/Karolinska Institute
- Norwegian Group on Inherited Cancer





# Diagnose & Investigate

What should professionals do in order to diagnose and investigate?

1. Clinical guidelines on diagnostics
2. Genetic screening
3. Genetic screening of newborns
4. Priority setting

# Institutes/persons to be responsible

- Fondazione IRCCS, Ospedale Maggiore Policlinico, Mangiagalli e Regina Elena, Italy
- Max Planck Institute for Molecular Genetics, Germany
- RIMV, the Netherlands



# POLICY DEVELOPMENT

Inform, Educate, Empower

Mobilize Community Partnerships

Develop Policies

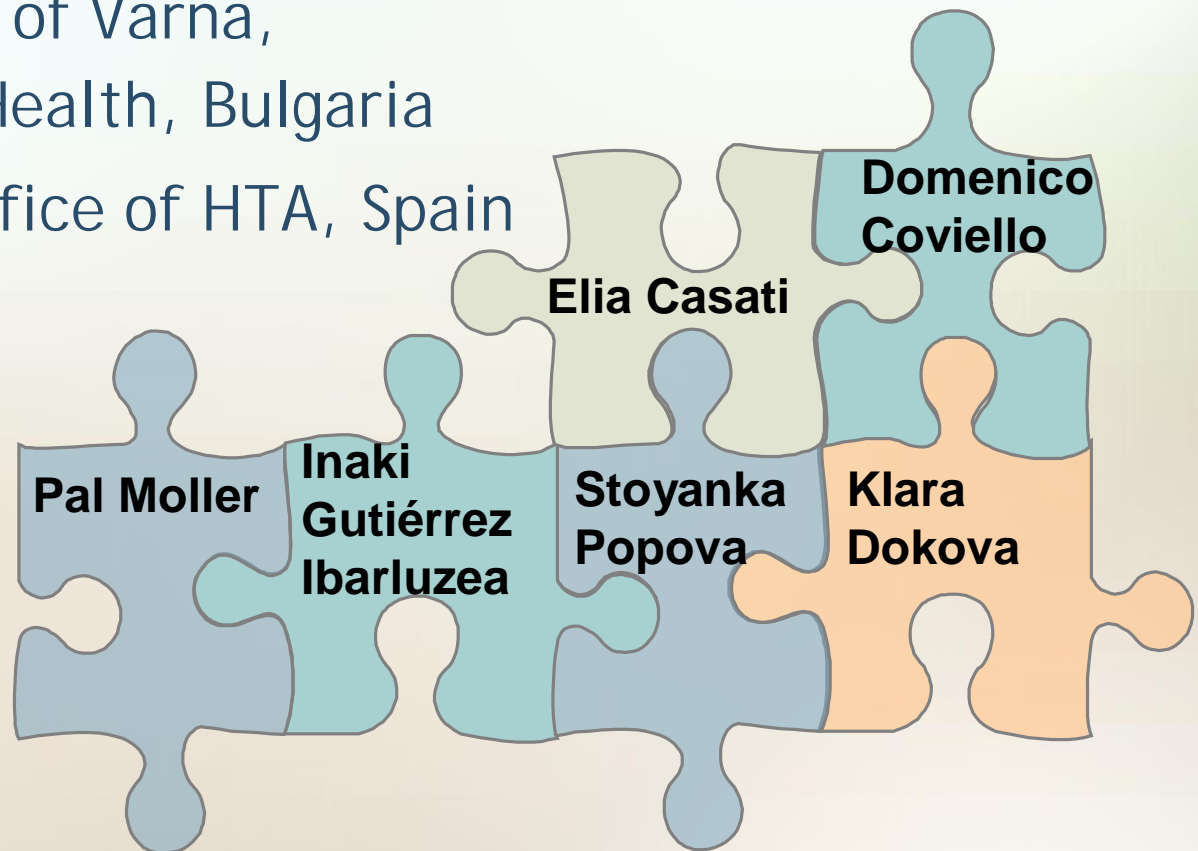
# Inform, Educate, Empower

What should professionals do to inform and educate?

1. Genetic/Genomic counselling
2. Risk communication
3. Media communication
4. Class education / school education / improvement of curricula of relevant courses
5. Establishment of information campaigns
6. Role of professionals involved in genome-based interventions
7. The role of persons/citizens
8. Health literacy

# Institutes/persons to be responsible

- Fondazione IRCCS, Ospedale Maggiore Policlinico, Mangiagalli e Regina Elena, Italy
- Norwegian Group on Inherited Cancer
- Medical University of Varna, Faculty of Public Health, Bulgaria
- Osteba, Basque Office of HTA, Spain



# Mobilize Community Partnerships

What should professionals do to mobilize community partnerships?

1. Education of professionals in professional-public communication
2. Information campaigns on mobilisation issues
3. Support of the activities of the NGOs
4. PPP and incentives

# Institutes/persons to be responsible

- University of Debrecen, Medical and Health Science Centre, Hungary
- Instituto Nacional de Saude Dr Ricardo Jorge, Portugal
- Fondazione IRCCS, Ospedale Maggiore Policlinico, Mangiagalli e Regina Elena, Italy
- Norwegian Group on Inherited Cancer



# Develop Policies

How policies are developed? By whom?  
When?

1. Setting objectives
2. Allocation of funds
3. Establishment of necessary facilities
4. Introduction of new genome-based innovations to HC
5. Participation of medical professionals in policy development
6. Epigenetical influence on policy development



# Institutes/persons to be responsible

- Institute for Public Health Genomics, University of Maastricht, the Netherlands
- Osteba, Basque Office for Health Technology Assessment  
Department of Health, Spain



# ASSURANCE

Enforce Laws

Link to/provide health care

Assure Competent Workforce

Evaluate

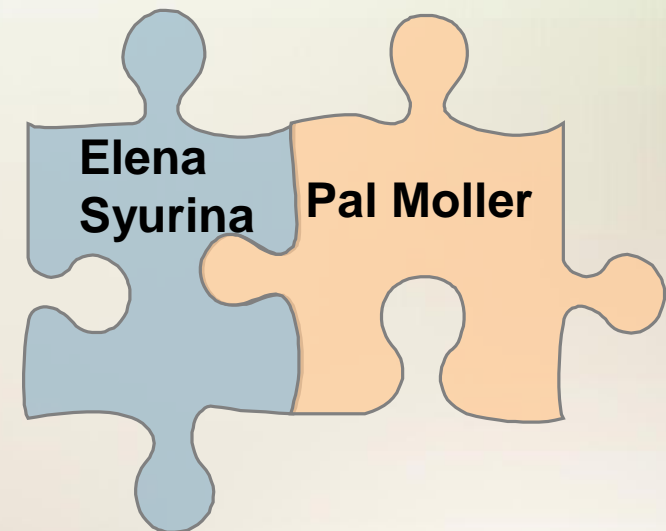
# Enforce Laws

How can professionals influence law enforcement? Which laws can protect their interests?

1. Protection of genetic information
2. Protection of rights of professionals
3. Intellectual property
4. Access to data

# Institute/person to be responsible

- Institute for Public Health Genomics, University of Maastricht, the Netherlands
- Norwegian Group on Inherited Cancer, Norway



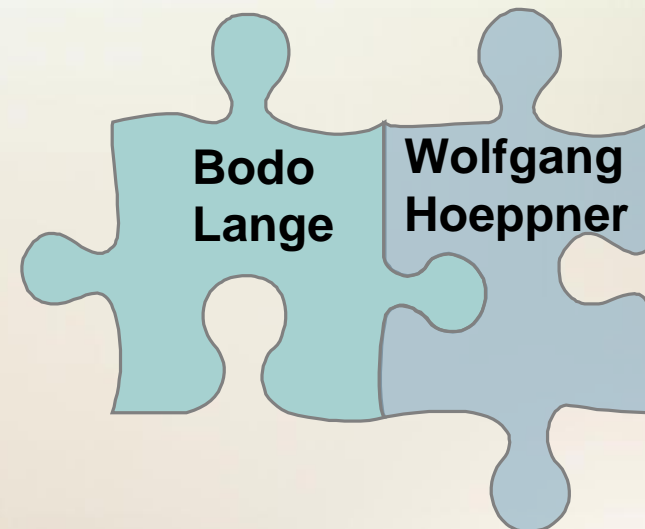
# Link to/provide health care

How professionals can provide health care?

1. Clinical guidelines
2. Standards for provision of HC
3. Access to samples
4. Provision of facilities
5. Preventive interventions
6. Pharmacogenomics
7. Epigenomic effects on HC

# Institutes/persons to be responsible

- Max Planck Institute for Molecular Genetics, Germany
- BioGlobe GmbH, Germany



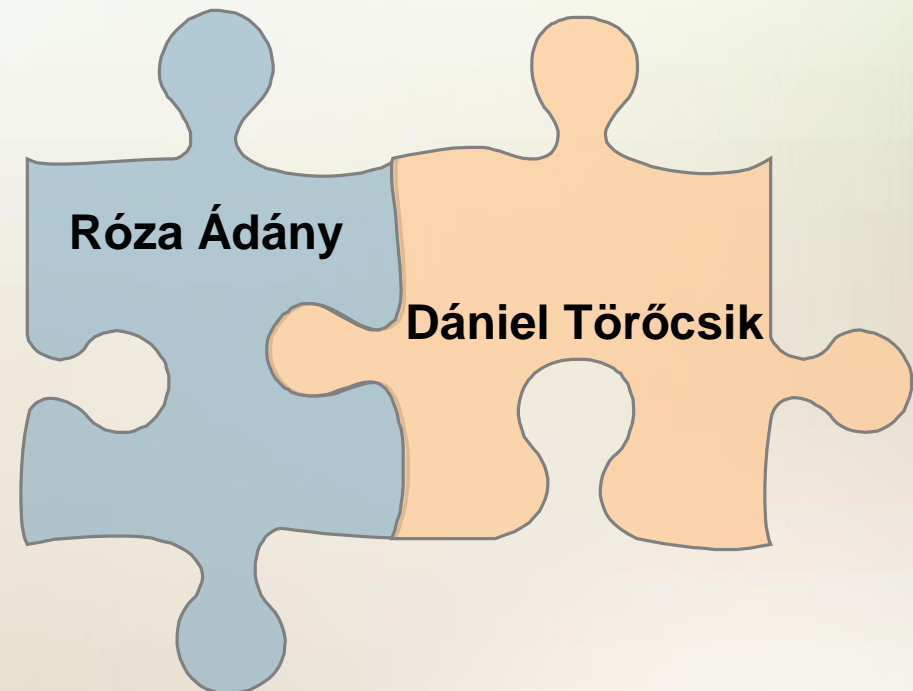
# Assure Competent Workforce

What training should workforce get? What kind of infrastructure and organization professionals should have?

1. Education of medical and health professionals
2. Education of policy professionals
3. Education of professionals involved in quality controlling and improvement
4. Education of professionals in health technology assessment

# Institute/persons to be responsible

- University of Debrecen, Medical and Health Science Centre, Hungary





# Questionnaire

## QUESTIONNAIRE ABOUT INTEGRATING THE GENOMICS/GENETICS INFORMATION INTO THE TRAINING PROGRAMMES OF PUBLIC HEALTH COURSES

1. Does your training programme contain any lectures/seminars regarding public health genomics/genetics?

Yes

No

2. If the answer is YES, what kind of training is delivered:

A. a complete course (MSc)

B. a short course (less than 30 hours)

C. lectures on public health genomics/genetics in another course

3. If the answer is NO, are you planning to launch:

A. a complete course (MSc)

B. a short course (less than 30 hours)

C. integrate parts into another course

D. don't plan to

24 countries

31 institutes

# Responses

## INTEGRATING THE GENOMICS/GENETICS INFORMATION INTO THE TRAINING PROGRAMMES OF PUBLIC HEALTH COURSES

The training programme contains any lectures/seminars regarding public health genomics/genetics

The answer is YES: 12

A. a complete course (MSc) - 0

B. a short course (less than 30 hours) - 7

C. lectures on public health genomics/genetics in another course - 5

The answer is NO: 19

planned to launch in the future:

Yes - 4

No - 15

# Public health genomics - Editors

Róza Ádány - Judit Sándor - Angela Brand

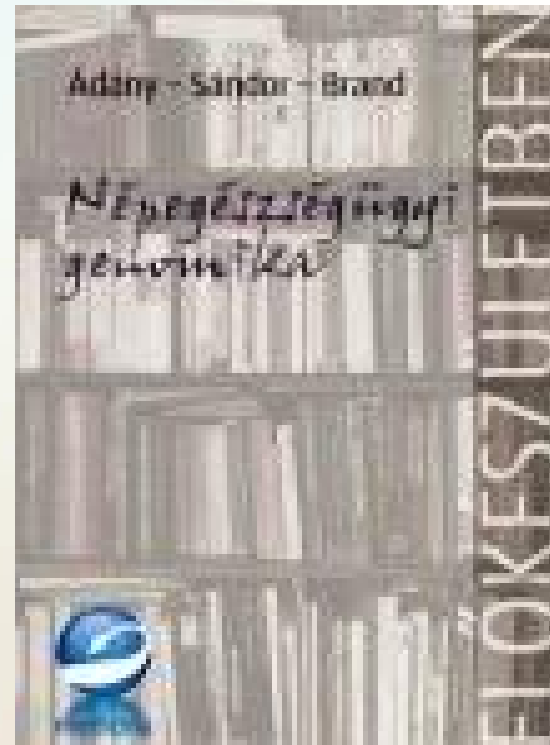


**Medicina, Budapest, in press**

# Public health genomics

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**Medicina, Budapest, in press**

# Public health genomics

## Chapters

- I. The human genome and its variations
- II. Human biobanks for public health research
- III. Methods to study genomic alterations
- IV. Molecular targets and tests for newborn screening
- V. Population-based genomic research focused on chronic non-communicable diseases: Malignancies, Cardiovascular diseases, Metabolic diseases
- VI. Genetic background of health behaviour (smoking, alcoholism, nutrition, etc)

# Public health genomics

## Chapters

- VII. Genetic susceptibility to communicable diseases (influenza, tbc, herpes virus and HIV infections, etc)
- VIII. Ethical aspects of public health genomics
- IX. Legal aspects of public health genomics
- X. European perspectives of legislation in connection with public health genomics
- XI. The European Public Health Genomic Network: its organization and functions

# Evaluate

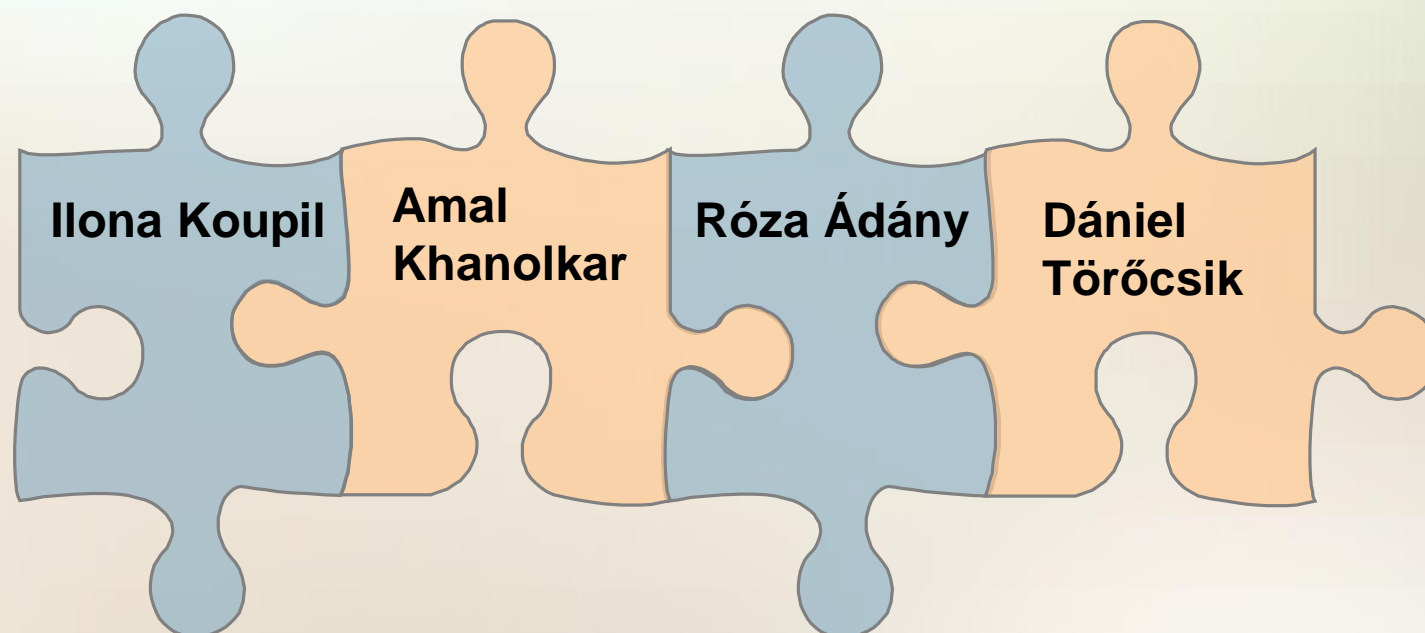
How should evaluation be done?

Using which methods?

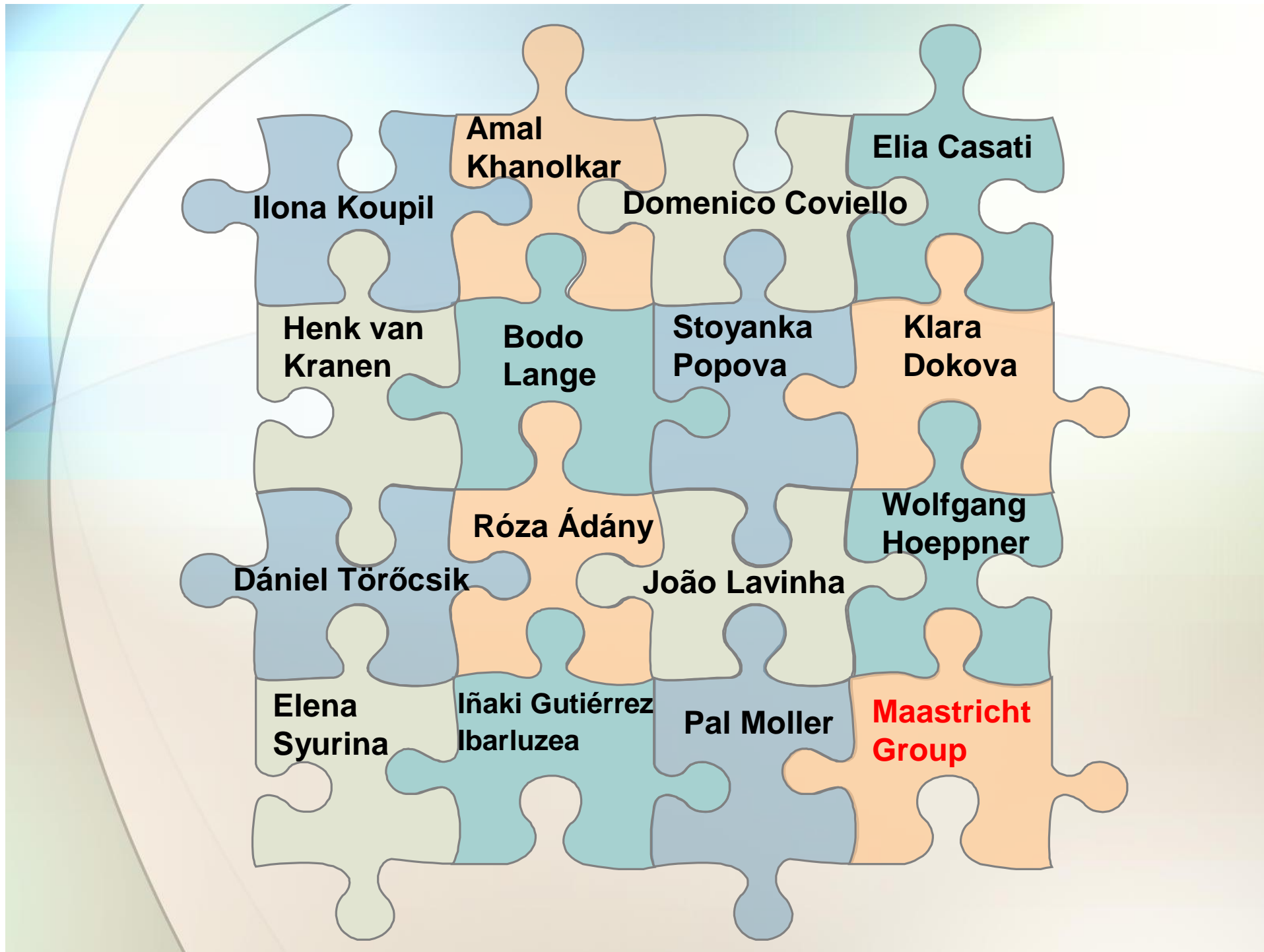
1. Provision of monitoring services
2. Guidelines for professionals on monitoring and data use

# Institute/persons to be responsible

- Centre for Health Equity Studies (CHESS) Stockholm University/Karolinska Institute
- University of Debrecen, Medical and Health Science Centre, Hungary







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