



**iPAAC**  
INNOVATIVE PARTNERSHIP  
FOR ACTION AGAINST CANCER

## **WP6 Genomics – Organizing the societal debate on the use of genomic information in healthcare**

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the Health Programme  
of the European Union

WP6 - Task 6.1: Applying genome information in health care: a paradigm shift in healthcare

Scope: Develop practical guidance for Member States on:

- 1) organizing the **societal debate** on ethical, legal and privacy issues on the use of genome information in healthcare

# Societal debate: why?

- Support
  - No genomics without data sharing
- Value laden
  - Genetics, medical research, privacy, ... - ELSI
- Good governance
  - Taking the perspective of citizens into account

➤ Many questions, no easy solution



# Dealing with difficult problems

$$-i\hbar\vec{\sigma} \cdot \vec{\nabla}(\phi^{(R)} - \phi^{(L)}) - i\hbar\frac{\partial}{\partial x_0}(\phi^{(R)} + \phi^{(L)}) + mc(\phi^{(R)} + \phi^{(L)}) = 0$$

$$i\hbar\vec{\sigma} \cdot \vec{\nabla}(\phi^{(R)} + \phi^{(L)}) + i\hbar\frac{\partial}{\partial x_0}(\phi^{(R)} - \phi^{(L)}) + mc(\phi^{(R)} - \phi^{(L)}) = 0$$

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$$-i\hbar\frac{\partial}{\partial x_0}\psi_A - i\hbar\vec{\sigma} \cdot \vec{\nabla}\psi_B + mc\psi_A = 0$$

$$i\hbar\vec{\sigma} \cdot \vec{\nabla}\psi_A + i\hbar\frac{\partial}{\partial x_0}\psi_B + mc\psi_B = 0$$

$$\begin{pmatrix} -i\hbar\frac{\partial}{\partial x_0} & -i\hbar\vec{\sigma} \cdot \vec{\nabla} \\ i\hbar\vec{\sigma} \cdot \vec{\nabla} & i\hbar\frac{\partial}{\partial x_0} \end{pmatrix} \begin{pmatrix} \psi_A \\ \psi_B \end{pmatrix} + mc \begin{pmatrix} \psi_A \\ \psi_B \end{pmatrix} = 0$$



# The use of genomic information in healthcare as a wicked problem



# Characteristics of a wicked problem



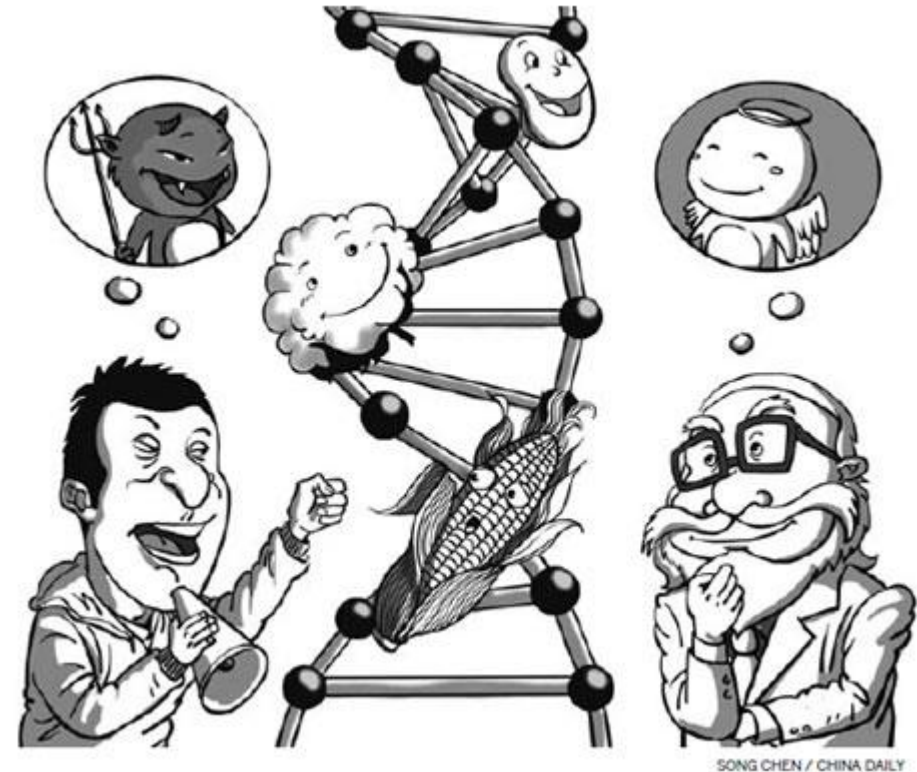
- Wicked problems are also characterized by the following:
- The solution depends on how the problem is framed and vice versa (i.e., the problem definition depends on the solution)
  - Stakeholders have radically different world views and different frames for understanding the problem.
  - The constraints that the problem is subject to and the resources needed to solve it change over time.
  - The problem is never solved definitively.



# Wicked problems and societal debate

Dealing with wicked problems:

- Authoritative
- Competitive
- Collaborative



# OVERVIEW OF INTERNATIONAL INITIATIVES

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- 9 initiatives (USA, UK, Europe)
- **General trends:**
- **Linked to government** : 8/9 supported by governmental organisation, 5/9 aim to influence policy makers
- **Public's opinions and attitudes** towards issues of genomics
- **Diversity of participants**
- Educate/**Inform** the public → in-depth debate
- Engage the public with **active methods** (for example: deliberation, vote, mock jury trial, report and recommendations to policy makers)



- **100 000 Genomes Project** (2013)
- **Methods:**
- Patient and public involvement:
  - PPI Network
  - Patient representation
  - Public events and debates
- National participants panel

## The 100,000 Genomes Project in numbers



**100,000** genomes



**70,000** patients and family members



**21** Petabytes of data.  
1 Petabyte of music would take 2,000 years to play on an MP3 player.



**13** Genomic Medicine Centres, and  
**85** NHS Trusts within them are involved in recruiting participants



**1,500** NHS staff  
(doctors, nurses, pathologists, laboratory staff, genetic counsellors)



**2,500** researchers and trainees from around the world

- **Goal** : ethical framework - recommendations for regulations and codes of conduct
- **Methods:**
  - Citizen panels
  - Surveys
  - Expert interviews
  - Workshops and conferences with stakeholders

sienna.

# EFFECTS OF PUBLIC DEBATE

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- Genome Diner (2012, funded by NIH)
    - Starter : questions
    - Main Course : debate
    - Dessert : conclusion
  - Effects on experts
    - Recognize the importance of engaging the public in genomics research
    - Understand the knowledge, perceptions and concerns of the public about genomics research
    - Enhance their capacity to answer public concerns and questions
- Public's trust in genomics research increases

**Table 4** Effect of democratic deliberation on attitudes toward policies for secondary findings, n = 64<sup>a</sup>

Proposed Policy	Baseline (Survey 1)			Post-DD session (Survey 2)			Follow-up (Survey 3)		
	Overall	Default	Choice	Overall	Default	Choice	Overall	Default	Choice
<b>Medically actionable</b> <i>Patients are given medically actionable results that are not related to the reason for the sequencing. Patients have a choice: They can ask to NOT be given these results.</i>									
%Agree	89.1	81.3	87.5	85.9	89.1	95.3	93.8	89.1	87.5
%Disagree	9.4	17.2	10.9	12.5	10.9	4.7	6.3	9.4	9.4
<b>Adult-onset conditions</b> <i>Children and their parents are not given results for adult-onset conditions that are not related to the reason for the sequencing. Children and their parents have no choice: They will not be given these results even if they want them.</i>									
%Agree	9.4	20.3	7.8	43.8 <sup>a</sup>	50.0 <sup>a</sup>	31.3 <sup>b</sup>	23.4 <sup>a</sup>	39.1 <sup>a</sup>	25.0 <sup>b</sup>
%Disagree	87.5	76.6	89.1	54.7 <sup>a</sup>	50.0 <sup>a</sup>	68.8 <sup>b</sup>	73.4 <sup>a</sup>	57.8 <sup>a</sup>	67.2 <sup>b</sup>
<b>Carrier status</b> <i>Patients are not given carrier status results that are not related to the reason for the sequencing. Patients have no choice: They will not be given these results even if they want them.</i>									
%Agree	4.7	14.1	4.7	21.9 <sup>a</sup>	31.3	15.6	7.8	23.4	6.3
%Disagree	98.4	84.4	93.8	75.0 <sup>a</sup>	68.8	84.4	90.6	73.4	90.6

<sup>a</sup>  $P \leq 0.01$ ; The  $p$  value is based on related samples Cochran's Q test, compared to baseline (Survey 1) response, adjusted for multiple comparison. Not all participants answered the question

<sup>b</sup>  $P \leq 0.05$ ; The  $p$  value is based on related samples Cochran's Q test, compared to baseline (Survey 1) response, adjusted for multiple comparison. Not all participants answered the question

Gornick, *et al.* "Effect of Public Deliberation on Attitudes toward Return of Secondary Results in Genomic Sequencing" (2014-2015, USA).



First iPAAC Stakeholder Forum, Brussels, 20 September 2018

# OUR CONTRIBUTION

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# CURRENT INITIATIVES

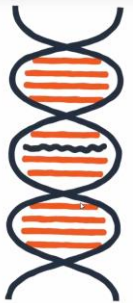
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- Focus group study
  - Involving patients in implementation of genomics in the clinic
- Citizens forum
  - Gaining insight in citizens' perspectives on ELSI regarding genomics

# FOCUS GROUPS

- 56 cancer patients were recruited to participate in 1+10 focus groups (2 - 8 participants per group)

- Participants were shown an informational video about NGS
  - (Youtube: 'Belgian Cancer Center' for Dutch and French version)



- Participants were asked to formulate an opinion on 8 theses about genomics



# FOCUS GROUP DISCUSSION

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## 8 theses

- Preconceptions (doubts, expectations)
- Role of health care professionals
- Right (not) to know?
- Information sharing
- Incidental findings
- Comprehensiveness of NGS testing
- Relevance for family members
- Future of genomics



# FOCUS GROUPS: GOAL

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The goal of the focus groups is to draft ‘informed’ informed consent guidelines, based on the experiences and opinions of patients.

- Balancing data from focus groups, international guidelines and legal and normative arguments
  - Stakeholder working group

With King Baudoin Foundation

- Internationally validated method: wicked societal problems
- 32 informed citizens share their views
  - Dialogue, no need for consensus
  - Help from a support team
  - Information provided by experts
  - Working towards balanced policy recommendations

ISSUE FRAMING WORKSHOP (23/02/2018): **EXPERTS**

The use of genome information in health care: identifying and discussing the ethical, legal and societal issues

INFORMATION BROCHURE (28/06/2018): **CITIZENS**

THREE WEEKENDS (September – December 2018): **CITIZENS**

FIRST REPORT -> **STAKEHOLDER** WORKSHOP (February 2019)

SECOND REPORT -> SYMPOSIUM (End of 2019)

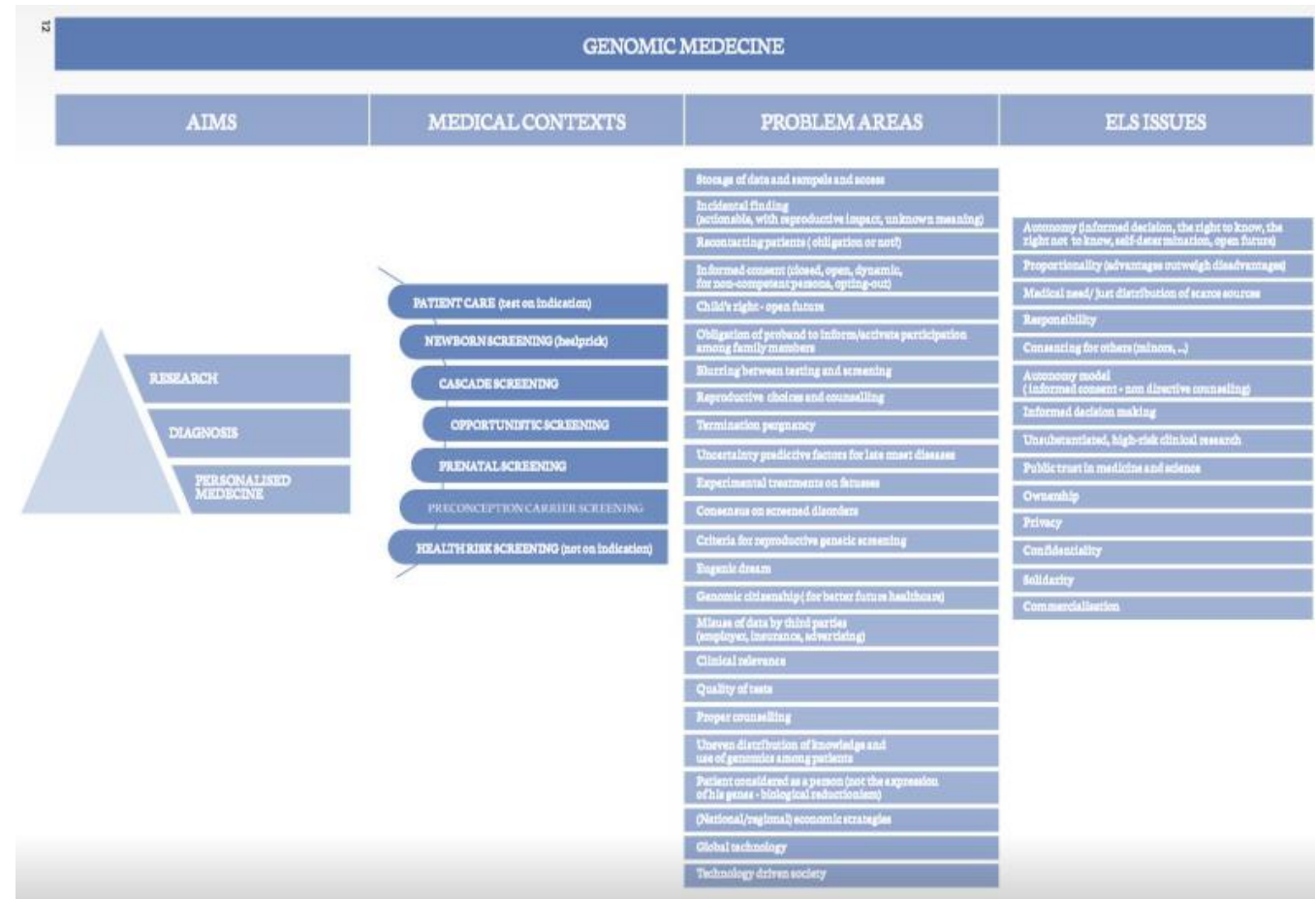


# ISSUE FRAMING WORKSHOP

## The use of genome information in health care: ethical, legal and societal issues

Report of the Issue framing workshop

Brussels, 23 February 2018

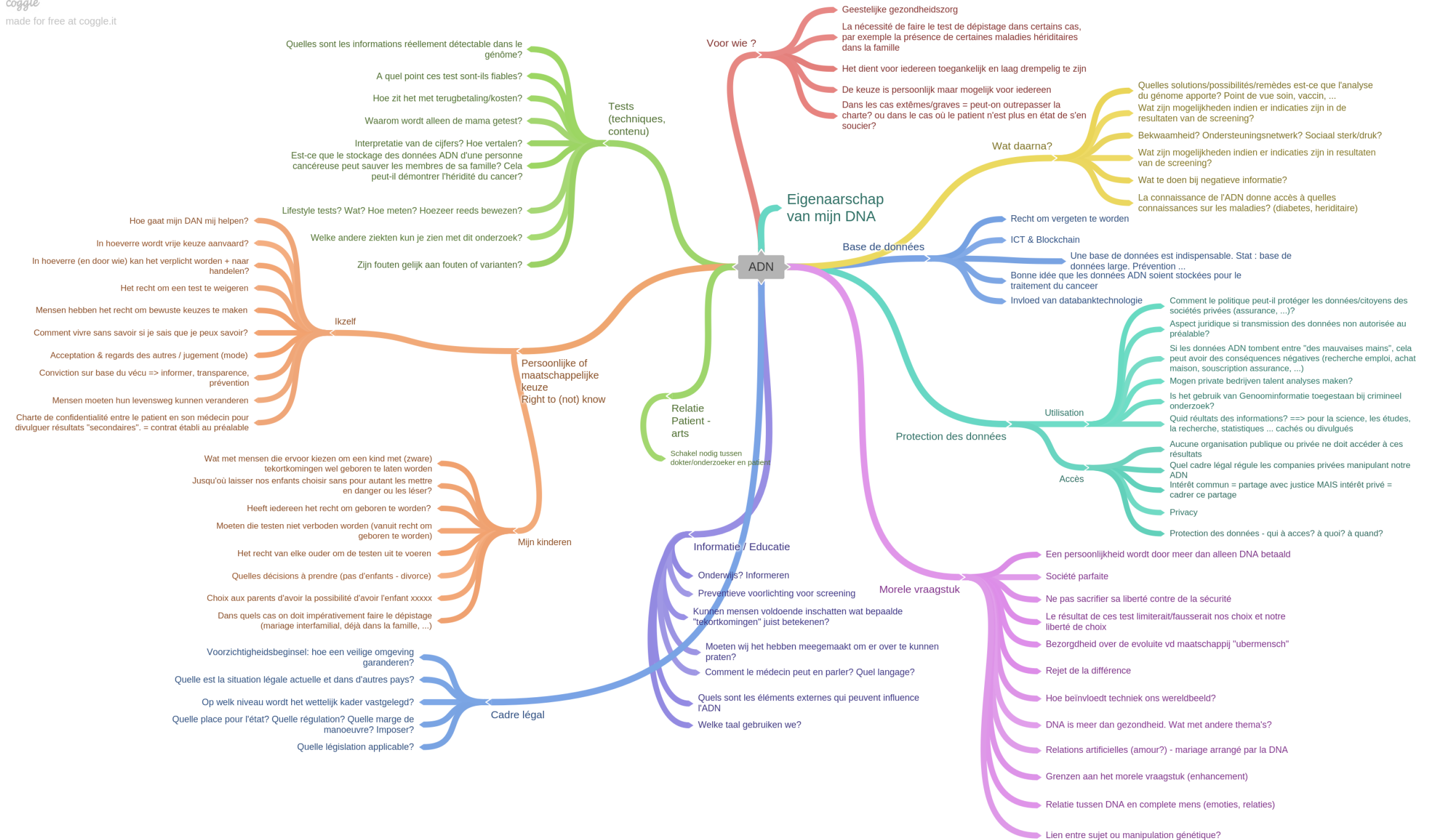


<https://www.kbs-frb.be/en/Activities/Publications/2018/20180712PP>

# INFORMATION BROCHURE



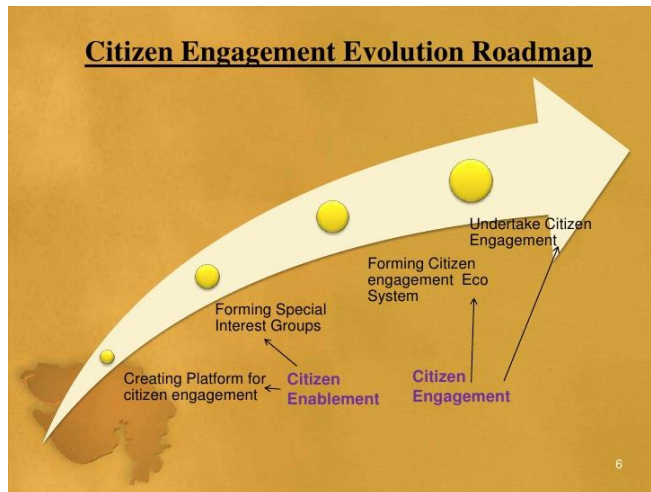
<https://www.kbs-frb.be/fr/Activities/Publications/2018/20180704PP>



## QUESTIONS?



## DO YOU KNOW ABOUT SIMILAR INITIATIVES?



## THANK YOU!

