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# IMAGE

## Innovative Management of Animal Genetic Resources

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Horizon 2020 FRAMEWORK PROGRAMME

**TOPIC: MANAGEMENT AND SUSTAINABLE USE OF GENETIC RESOURCES**

Topic identifier: SFS-07b-2015

**Type of Action: Research and Innovation Action (RIA)**

### DELIVERABLE D1.1

Ethical approvals for the collection of personal data regarding the sociological analysis of the innovation challenges for animal resources

#### Abstract:

A good understanding of the various viewpoints of stakeholders is required to improve and ensure a sustainable management of AnGR. Therefore a survey and in-depth interviews with actors will be undertaken.

Due date of deliverable: Month 10

Actual submission date: Month 16

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Duration: 48 months

Organisation name of lead contractor: BOKU

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## Executive Summary

<p><b>Background</b></p>	<p>A multi-actor perspective on the management of animal genetic resources helps to better address the needs and demands from the various stakeholders.</p>
<p><b>Objectives</b></p>	<ul style="list-style-type: none"> <li>• Identify needs, preferences and attitudes of different stakeholders towards animal genetic resource management</li> <li>• Increase awareness on the importance of animal genetic resource management</li> <li>• Identify options for branding and marketing of local breeds</li> </ul>
<p><b>Methods</b></p>	<p>In Task 1.2 two complementing methods will be applied. In a first step an on-line survey will be developed and a range of different stakeholders will be invited to respond.</p> <p>In a second step face-to-face in-depth interviews with key informants will be performed.</p>
<p><b>Results &amp; implications</b></p>	<p>A better understanding on the different attitudes of stakeholders helps to propose possible adjustments in the current management of gene banks, and particularly for sampling rules and distribution procedures.</p> <p>This task will inform other tasks of WP1, but will also give input to other WPs of the IMAGE project: WP2 for gene bank operations, WP3 for reproductive biotechnologies, WP4 for genomic characterization, WP5 for the data portal, WP6 for methods of use, WP7 for training needs.</p>

## 1. Approach

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The IMAGE project aims to enhance the use of genetic collections and to upgrade animal gene bank management. IMAGE will further develop genomic methodologies, biotechnologies, and bioinformatics for a better knowledge and exploitation of animal genetic resources.

A wide range of different stakeholders are involved in the conservation of animal genetic resources. This heterogeneity of stakeholders leads to a wide range of expectations, needs and demands. Therefore, IMAGE project wishes to engage in a dialogue with stakeholders in order to get a better understanding on expectations. The information gathered during these interactions will be used in a feedback mechanism as an input for other WPs.

The aim of task 1.2 in WP1 is to document the current perceptions of a wide range of stakeholders on conservation strategies and its importance in the presence, but also for future exploitation of genetic diversity of animal genetic resources.

## 2. Description

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This deliverable describes the methodology used for the task 1.2 “Sociological analysis of the innovation challenges for animal genetic resources”. The aim of this task is to identify the needs, attitudes and preferences towards management and use of animal genetic resources in general, and gene banking in particular, by different stakeholders. For this purpose two different methodologies will be applied. An on-line survey will be developed and shared with a large number of different actors. In addition, in-depth interviews will be carried out to get more detailed insights from different stakeholders.

This deliverable addresses ethical issues related to the data collection, where also personal data will be compiled and used for analysis. Therefore, this deliverable is a guide for researchers involved in this task. Researchers should reflect on and address the possible ethical implications of such a research. Research must confirm to all legal requirements. This includes full compliance with relevant data protection legislation.

## 3. General guiding principles

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The following guiding principles are formulated:

### 3.1 Beneficence

- Concern for the interests of the participant must always prevail over the interests of science and society.
- The research should be preceded by careful assessment of predictable risks in comparison with foreseeable benefits to the participants or to others.
- Money or other inducements should not be used to encourage participation.

### **3.2 Integrity**

- The research should be scientifically sound and the purpose should be to contribute to knowledge.
- The research should be undertaken and supervised by those who are appropriately qualified and experienced, and they must be accountable for the research they undertake. Steps should therefore be taken to ensure the retention of data for possible auditing. Procedures for data storage are described in the data management plan of IMAGE project.
- IMAGE requires principle investigators to take reasonable steps to ensure the research integrity of their colleagues' research, e.g. listen to interview tapes, check lab books, or examine data sets.

### **3.3. Informed consent**

- Each potential participant must be adequately informed of the aims, methods, anticipated benefits and potential hazards of the research and any discomfort it may entail.
- Any documentation given to potential participants should be comprehensible and there should be an opportunity for them to raise any issues of concern;
- Consent should normally be in writing and records of consent should be maintained.
- Potential participants must be informed that they are free to withdraw consent to participation at any time.
- Contact details should be made available so that participants can get in touch even after data-gathering has been concluded.

### **3.4 Confidentiality/Anonymity**

- All research should conform to data protection legislation.
- Details that would allow individuals to be identified should not be published, or made available, to anybody not involved in the research unless explicit consent is given by the individuals concerned, or such information is already in the public domain.

- All reasonable steps should be taken to ensure that confidential details are secure.

### **3.5. Independence and impartiality**

Researchers should be honest with respect to the conduct of their research from inception to publication. Conflicts of interests are not necessarily unethical but should be declared and dealt with appropriately.

## **4. Description of Methodology**

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### **4.1 On-line survey**

In Task 1.2 an on-line survey for different stakeholders is developed. Stakeholders are gene bank managers, breeders' associations, NGOs, governmental offices and public institutions dealing with AnGR, universities and research organisations.

In the introductory text of the on-line survey participants will be informed that

- their data information is kept anonymous
- data will be used for scientific publications
- data will be shared with IMAGE project partners

Participants have to actively agree to these terms by clicking a button "I agree with the conditions". If they do not agree, they will not be able to proceed with the on-line survey.

The information will be stored on a server on a restricted area maintained by BOKU institution. The data will be handled in a way that one cannot trace back individual respondents. The principles of the data management plan will be followed for data storage.

Annex 1. Questionnaire of on-line survey

### **4.2 In-depth interviews**

For the in-depth interviews a similar approach to ensure confidentiality of collected data will be applied.

These interviews are complementary to the on-line survey. They will provide deeper understanding on the questions related to AnGR management, but will not enquire about personal data related to other topics such as political ideas or religious beliefs. It is planned to carry out around 15-20 in-depth interviews.

Possible interview partners will be asked by e-mail, if they are willing to participate in the IMAGE-project and provide their expertise in an interview. In the first contact they will be already informed that the data generated in the interviews will be used for scientific publications.

Before the actual interview can be carried out interviewees have to agree by signing a declaration that the interview is recorded and that information will be later on used for scientific purposes. Interviewees will have the right to read scientific manuscripts before submission to a journal to check if they were correctly cited and their opinions are presented in the right way. If they agree, they will provide a written statement that they agree with the submission of the manuscript.

Annex 2. Consent form

### **Data storage**

In the data management plan of IMAGE a detailed description of the storage and use of different data sets is made.

Regulations for publications and getting prior consent from project partners are set out in the consortium agreement, which was signed by all project partners.

## **5. Acknowledgement**

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For preparation of this deliverable the report “D8.3.1 Report on ethical approvals and approvals for the collection of personal data” from the AUGGMED project was consulted and used.

## 6. Annex 1. Questionnaire for on-line survey of Task 1.2

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### Section GI: General Information

[GI12] Text Input

Email

"Before starting the survey: if you would like to receive updates on the outcomes of this survey and the IMAGE..."

**GI12\_01** [01]

Free text

[GI01] Multiple Choice

Institution/Line of work

"Institution/Line of work:"

**GI01** Institution/Line of work : Residual option (negative) or number of selected options

Integer

**GI01\_01** Science

**GI01\_02** Bio bank

**GI01\_03** International organisation (e.g. FAO)

**GI01\_04** Breeding company

**GI01\_05** NGO

**GI01\_06** Breeder/Breed organisation

**GI01\_07** Government

**GI01\_08** Biotech service provider

**GI01\_09** Extension service provider

**GI01\_10** Other (please specify)

1 = Not checked

2 = Checked

**GI01\_10a** Other (please specify) (free text)

Free text

[GI03] Selection

Highest level of education

"Highest level of education"

**GI03** Highest level of education

1 = Primary education

2 = Secondary education

3 = Tertiary education (bachelor level)

4 = Tertiary education (master level)

5 = Postgraduate education (PhD level)

-9 = Not answered

[GI04] Selection

Age group

"Age group"

**GI04** Age group

1 = <18

2 = 18-24

3 = 25-39

4 = 40-59

5 = 60-79

6 = >80

-9 = Not answered

[GI05] Selection

Gender

"Gender"

**GI05** Gender

- 1 = Male
- 2 = Female
- 3 = Other
- 9 = Not answered

[GI06] Dropdown Selection

Nationality

"Nationality"

**GI06** Nationality

- 1 = Austria
- 2 = Belgium
- 3 = Bulgaria
- 4 = Croatia
- 5 = Republic of Cyprus
- 6 = Czech Republic
- 7 = Denmark
- 8 = Estonia
- 9 = Finland
- 10 = France
- 11 = Germany
- 12 = Greece
- 13 = Hungary
- 14 = Iceland
- 15 = Ireland
- 16 = Italy
- 17 = Latvia
- 18 = Lithuania
- 19 = Luxembourg
- 20 = Malta
- 21 = Netherlands
- 22 = Norway
- 23 = Poland
- 24 = Portugal
- 25 = Romania
- 26 = Slovakia
- 27 = Slovenia
- 28 = Spain
- 29 = Sweden
- 30 = Switzerland
- 31 = United Kingdom
- 32 = Other (please specify)
- 9 = Not answered

**GI06\_32** Other (please specify)

Free text

[GI07] Multiple Choice

Species

"Which species are you working with?"

**GI07** Species: Residual option (negative) or number of selected options

Integer

**GI07\_01** Cattle

**GI07\_02** Sheep

**GI07\_03** Goats

**GI07\_04** Poultry

**GI07\_05** Pigs

**GI07\_06** Other (please specify)

1 = Not checked

2 = Checked

**GI07\_06a** Other (please specify) (free text)

Free text

[GI08] Multiple Choice

Rare/commercial breeds

"Are you working with..."

**GI08** Rare/commercial breeds: Residual option (negative) or number of selected options

Integer

**GI08\_01** Rare breeds

**GI08\_02** Commercial breeds

**GI08\_03** None of the above

1 = Not checked

2 = Checked

[GI09] Multiple Choice

Conservation involvement

"Are you involved in... (chose one or several options)"

**GI09** Conservation involvement: Residual option (negative) or number of selected options

Integer

**GI09\_01** Ex-situ conservation of rare breeds (e.g. bio banks)

**GI09\_02** In-situ conservation of rare breeds (e.g. live populations)

**GI09\_03** None of the above

1 = Not checked

2 = Checked

[GI10] Multiple Choice

Bio bank involvement

"Describe your involvement with bio banks. (chose one or several options)"

**GI10** Bio bank involvement: Residual option (negative) or number of selected options

Integer

**GI10\_01** User

**GI10\_02** Donor

**GI10\_03** Manager

**GI10\_04** None of the above

1 = Not checked

2 = Checked

[GI11] Selection

## Contact

"How often are you involved/in contact with a bio bank?"

### GI11 Contact

- 1 = Monthly
- 2 = Yearly
- 3 = Less often than yearly
- 4 = Never
- 9 = Not answered

## Section BB: Bio bank questionnaire

### [BB01] Horizontal Selection

#### Importance of genetic management

"In your opinion, what is the importance of animal genetic resources management?"

### BB01 Importance of genetic management

- 1 = Very low
- 2 = Low
- 3 = Medium
- 4 = High
- 5 = Very high
- 1 = Don't know
- 9 = Not answered

### [BB02] Selection

#### Change of importance

"In your opinion, will this importance change in your country in the next 10 years?"

### BB02 Change of importance

- 1 = Yes, the importance will increase.
- 2 = No, the importance will remain stable.
- 3 = Yes, the importance will decrease.
- 9 = Not answered

### [BB03] Scale (fully labeled)

#### Concern about loss

"Are you concerned about loss of..."

**BB03\_01** Rare breeds

**BB03\_02** Genetic diversity in commercial breeds

1 = Not at all

2 = No

3 = Somewhat

4 = Yes

5 = Very much

-1 = Don't know

-9 = Not answered

[BB04] Scale (fully labeled)

Tools for genetic management

"Should the following tools for animal genetic resources management be used more or avoided in future?"

**BB04\_01** Conventional breeding programs

**BB04\_02** Bio banks (gene banks, genomic banks)

**BB04\_03** In-situ conservation (on farm)

**BB04\_04** Ex-situ conservation (live animals in zoos, bio banks)

**BB04\_05** Genomic selection

**BB04\_06** Gene editing

**BB04\_07** Sexed semen

**BB04\_08** Embryo transfer

**BB04\_09** Artificial insemination

**BB04\_10** In-vitro fertilisation

1 = Use more

2 = Maintain

3 = Avoid in future

-1 = Don't know

-9 = Not answered

[BB05] Selection

Bio bank awareness

"Are you aware of bio banks (storage of semen, embryos etc and/or isolated DNA, tissue, etc). for farm animal..."

**BB05** Bio bank awareness

1 = Yes

2 = No

-9 = Not answered

[BB06] Scale (fully labeled)

Bio bank importance

"Estimate the importance of a bio bank for animal genetic resources management in the following areas."

**BB06\_01** Biodiversity

**BB06\_02** Research

**BB06\_03** Commercial

**BB06\_04** Heritage

**BB06\_05** Characterisation of breeds

**BB06\_06** Restoring of breeds/lines

**BB06\_07** Creating new breeds/lines

**BB06\_08** Development of new technologies

1 = Very low

2 = Low

3 = Medium

4 = High

5 = Very high

-1 = Don't know

-9 = Not answered

[BB07] Scale (fully labeled)

Bio bank access

"In your opinion, who should have what kind of access to the contents of bio banks?"

**BB07\_01** Breed societies

**BB07\_02** Private research institutions

**BB07\_03** Public research institutions

**BB07\_04** Farmers

**BB07\_05** Government bodies

**BB07\_06** International organisations (e.g. FAO)

**BB07\_07** Commercial organisations

**BB07\_08** NGOs

1 = Free access

2 = Access at a fee

3 = No access

-1 = Don't know

-9 = Not answered

[BB08] Scale (fully labeled)

Funding proportion

"In your opinion, what should be the proportion of public/private funding of bio banks in the following areas?"

**BB08\_01** Collection of genetic material

**BB08\_02** Characterisation of genetic material

**BB08\_03** Management of genetic material (running costs)

**BB08\_04** Facilitating access to genetic material

1 = 100% PUBLIC - 0% PRIVATE

2 =

3 =

4 =

5 =

6 = 50% PUBLIC - 50% PRIVATE

7 =

8 =

- 9 =
- 10 =
- 11 = 0% PUBLIC - 100% PRIVATE
- 1 = Don't know
- 9 = Not answered

#### [BB09] Ranking

##### Collection strategies

"Please rank the following collection strategies in order of importance in your opinion!  
(drag&drop the boxes...)"

**BB09\_01** Collecting from the most endangered breeds

**BB09\_02** Collecting from breeds with highest genetic distance (Between breed diversity)

**BB09\_03** Collecting from breeds with highest within-breed diversity

**BB09\_04** Collecting from currently profitable breeds/individuals

**BB09\_05** Collecting from breeds/individual with desirable traits

- 1 = Rank 1
- 2 = Rank 2
- 3 = Rank 3
- 4 = Rank 4
- 5 = Rank 5
- 9 = Not ranked

#### [BB10] Scale (fully labeled)

##### Participation

"How much of a say should each of these institutions have about the contents of the bio banks?"

**BB10\_01** Breed societies

**BB10\_02** Private research institutions

**BB10\_03** Public research institutions

**BB10\_04** Farmers

**BB10\_05** Government bodies

**BB10\_06** International organisations (e.g. FAO)

**BB10\_07** Commercial organisations

**BB10\_08** NGOs

1 = No say at all

2 =

3 =

4 =

5 = Full authority

-1 = Don't know

-9 = Not answered

[BB11] Scale (fully labeled)

Trust

"How much do you trust the following types of organisation in relation to safekeeping of biological material ..."

**BB11\_01** Public organisations

**BB11\_02** Private organisations

**BB11\_03** NGOs

**BB11\_04** Private-public partnerships

1 = No trust at all

2 =

3 =

4 =

5 = Full trust

-1 = Don't know

-9 = Not answered

[BB12] Horizontal Selection

Adequacy

"Do you think that bio banks currently suit the needs of conservation breeding?"

**BB12** Adequacy

1 = Not at all

2 = Mostly not

3 = Somewhat  
4 = Mostly  
5 = Fully  
-1 = Don't know  
-9 = Not answered

[BB13] Text Input

Adequacy 2

"If you indicated that you think that bio banks do not fit the needs of conservation breeding ('Not at all' o..."

**BB13\_01** [01]

Free text

[BB14] Scale (fully labeled)

Integration

"Please rate what should be in your opinion the degree of integration between countries in the following areas"

**BB14\_01** General information about samples

**BB14\_02** Genetic data

**BB14\_03** Genetic material

1 = National independence  
2 =  
3 =  
4 =  
5 = Full European integration  
-1 = Don't know  
-9 = Not answered

[BB16] Scale (fully labeled)

Satisfaction

"Considering the bio bank(s) you know/work with, how satisfied are you with their..."

**BB16\_01** General organisation

**BB16\_02** Data management

### **BB16\_03** Genetic material management

- 1 = Not at all
- 2 =
- 3 = Somewhat
- 4 =
- 5 = Fully
- 1 = Don't know
- 9 = Not answered

[BB15] Multiple Choice

Ownership

"If a full European/international integration were implemented, who should own the intellectual property?"

**BB15** Ownership: Residual option (negative) or number of selected options

Integer

**BB15\_01** Donor country, government (where samples are taken)

**BB15\_02** Storing country, government

**BB15\_03** Free access to signatory countries ("public goods")

**BB15\_04** Donor of samples (individual, organization, institution)

**BB15\_05** Host Institution of bio bank

**BB15\_06** Other (please specify)

- 1 = Not checked
- 2 = Checked

**BB15\_06a** Other (please specify) (free text)

Free text

[BB17] Text Input

Suggestions

"If you have any further ideas or suggestions about the management of genetic resources of farm animals, plea..."

## 7. Annex 2. Consent form

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Consent for participation in a research interview

IMAGE

Innovative Management of Animal Genetic Resources

funded by

H2020 - The European Union Framework Programme for Research and Innovation

I agree to participate in a research project “IMAGE-Innovative Management of Animal Genetic Resources” (Grant Agreement Number: 677353) led by Dr. Michèle Tixier-Boichard from INRA (French National Institute for Agricultural Research). This project is designed to enhance the use of genetic collections and to upgrade animal gene bank management. Interviews aim to gather information about needs, attitudes and preferences towards management and use of animal genetic resources in general and gene banking in particular by different stakeholders.

1. **INFORMED CONSENT:** I have been given sufficient information about this research project. The purpose of my participation as an interviewee in this project has been explained to me and is clear.

2. **VOLUNTARY CONSENT:** My participation as an interviewee in this project is voluntary. There is no explicit or implicit coercion whatsoever to participate. I understand that I will not be paid for my participation. I have the right not to answer any of the questions. If I feel uncomfortable in any way during the interview session, I have the right to decline to answer any question or to withdraw from the interview.

3. **ANONYMITY AND CONFIDENTIALITY:** I understand that any summary interview content, or direct quotations from the interview, that are made available through academic publication or other academic outlets will be anonymized so that I cannot be identified, and care will be taken to ensure that other information in the interview that could identify myself is not revealed. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions.

6. **DATA COLLECTION AND MANAGEMENT PROCESS:** I approve the following:

- The interview will be recorded by the research team and transcribed by an independent transcriber who has signed a confidentiality agreement with them
- I will be provided, free of charge, the transcript and given the opportunity to correct any factual errors
- The transcript of the interview will be analysed by two IMAGE project’s internship fellows under the supervision of Dr. Maria Wurzinger (Division of Livestock Sciences at BOKU, Austria) and Dr. Antoine Doré (National Institute for Agricultural Research, France).
- Access to the interview transcript will be limited to research investigators in charge of the analysis and researchers with whom they might collaborate as part of the research process
- A short anonymized abstract of the interviews will be shared with all IMAGE partners
- The actual recording will be destroyed by the end of the project.

7. I have read and understood the points and statements of this form. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

8. I have been given a copy of this consent form co-signed by the interviewer.

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Participant's Signature Date

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Researcher's Signature Date

For further information about the research and for any request for access, modification, rectification and deletion of personal information collected, please contact: Dr. Antoine Doré (antoine.dore@inra.fr)