

PUBLIC OUTREACH FOR BIOBANKS

Enhancing knowledge, gaining trust and increasing
citizen participation





Welcome

Dear biobank and BBMRI.nl cohort managers,

This manual provides the strategy and tools to deliver an interactive public outreach day aimed at promoting public engagement and participation in Netherlands biobanks. Its findings and recommendations are based on interviews with biobank representatives to discover practical approaches, tools and communications materials that could facilitate public outreach in your institution. The manual describes the general public's awareness of and attitudes towards biobanks as well as the different scenarios and challenges faced by biobanks. The aims of a public outreach and communications strategy are discussed, together with possible communication messages, information material and activities. A glossary of concepts central to biobanking is provided in order to facilitate consistency in communications.

We hope that this manual will help you increase the public awareness and public engagement with your facility. Please do not hesitate to contact info@bbmri.nl if you have questions or comments.

Best regards,

BBMRI.nl



Executive Summary

Because biobanks contain authorized biomaterial from individual patients, they fundamentally rely on citizen participation. Yet it also remains a fact that few members of the general public are aware of their existence or their important role in biomedical research. Public outreach by biobanking institutions is one way public awareness of biobanking and its importance can be improved. By creating a positive attitude towards biobanks and the biomedical research they enable, people will be able to recognize their worth for science and society and acquire greater trust in biobanking institutions.

The most important messages to communicate to the public are a basic explanation of biobanks and biobank privacy regulations. These communication messages can be conveyed via informational material and interactive activities such as talks, demonstrations and games for adults and children that deepen their learning experience and attitude formation. An open dialogue with the public about biobanking is essential.

An open day or science festival is an ideal opportunity to connect scientists, scientific institutions and facilities such as biobanks directly with the public. However, the multifaceted nature of the target audience at a public outreach event - age groups, education levels, ethnicities and personal interests - poses special challenges that need to be considered. A mix of communication tools and approaches is necessary to convey the benefits of biobanks to as broad an audience as possible.



Table of Content

WELCOME	i
EXECUTIVE SUMMARY	ii
TABLE OF CONTENT	iii
1 WHY THIS MANUAL?	1
1.1 Biobanks: Unknown is unloved	1
1.2 Why now?	1
1.3 How to use this manual	2
2 AIMS AND STRATEGY FOR PUBLIC OUTREACH	3
3 COMMUNICATION MESSAGES	6
4 THE RIGHT SETUP AND CONTENT	8
4.1 How to reach your audience	10
4.2 Information Material and Activities	11
5 BIOBANK GLOSSARY	14
6 REFERENCES	17



1 Why this manual?

1.1 BIOBANKS: UNKNOWN IS UNLOVED

To realize the full potential of biobanks in biomedical research, biobank institutions depend on citizen participation. However, the majority of the general public are largely uninformed about biobanks and their role in science and society.

For the minority who are familiar with the concept of biobanks, they are sometimes worried about the application, safety and privacy of their biological material and personal data. According to biobanken.nl, potential biobank donors are often worried that data stored in biobanks will be accessible to third parties such as insurance companies, and could therefore be used prejudiciously. Another prominent fear expressed by patients is that if they allow their biological material to be used in research, none of the material will be left to inform their diagnosis and they may not therefore receive the right treatment. Some biobank donors are unaware that they have the legal right to withdraw from a study, which makes them anxious about participation (Biobanken Nederland, 2020). So even those who do know about biobanks are not completely informed, potentially hampering their trust in biobank institutions.

These examples clearly show the value of increased public outreach by biobanks. The importance of biobanks for every individual in society needs to be conveyed and widespread trust in biobanks and biomedical research needs to be built.

1.2 WHY NOW?

Changing regulations bring new opportunities, which makes this the right moment to start a conversation with the public about biobanks. With implementation of the [Dutch Code of Conduct \(Goed Gebruik\)](#), and more recently the General Data Protection Regulation (GDPR; *Algemene Verordening Gegevensbescherming* AVG), views on the acceptable use of personal biomaterial and data for research are changing. Some organizations are still challenged by the aftermath of GDPR, a situation that may be resolved when the Netherlands' planned Body Material Control Act (*Wet zeggenschap lichaamsmateriaal* Wzl) comes into force. These recent and planned developments put the use of biomaterial and data under the magnifying glass. While it may complicate the issue for biobank organizations, the legal profession and politicians, it is important that the perspective of the general public on biobanking is taken into account, particularly with respect to privacy. The upcoming Wzl makes it more important than ever for biobanks to open a dialogue with the public and make the general public aware of how biobanks operate and deal with privacy issues, because one of its aims is to provide an unambiguous framework for what can be done with human biomaterial that is no longer needed for a patient's medical treatment or diagnosis. In principle, the biomaterial should only be stored and used for research purposes if the donor has



actively given permission for it to be used in research. The starting point of this law is therefore informed consent, with any exceptions heavily regulated. First and foremost, the public therefore needs to be better informed about consent.

The new regulations will put the spotlight on biobanks and the fact that research derived from the biomaterial they contain should be used for the common good. Biobank donors should no longer be considered simply as sources of biomaterial, they should be considered as partners in research. To support that goal, BBMRI.nl has developed a guideline for involving patients and the public in the governance of biobanks and registries. The guideline document '[The donor as partner](#)' helps biobanks to set up and maintain a donor participation and cooperation structure suited to both their situations and needs.

1.3 HOW TO USE THIS MANUAL

Due to the responsibilities and workload of biobanks, it is understandable that attention and resources for public outreach are often limited. Nevertheless, some biobanks are already very active in public outreach and have gained a lot of expertise and experience. BBMRI.nl is keen to emphasize that public outreach can be performed individually and flexibly, yet still contribute to the bigger picture in terms of raising public awareness of biobanks.

To make any public outreach initiative by your biobank, large or small, this manual offers you:

- elaborated communication messages
- tools and approaches to convey the messages to the target audience
- information material for adults
- activities for children with various levels of required effort
- a glossary of central biobank terms

The manual is designed to facilitate direct engagement with the public, for example, in the form of an open day or as part of a more general science festival such as one of the Netherlands' Weekend of Science (*Weekend van de Wetenschap*) events. In addition, all the provided material can also be used for internal communication with colleagues or as part of an open day to give their families an insight into the biobank workplace. BBMRI.nl encourages you to use this manual and the activities it outlines in ways that most suit your biobank and that are compatible with your current priorities and time schedules.

By joining forces in public outreach, we can highlight the importance and achievements of biobanks to the general public in order to build trust and increase citizen participation. Public events such as 'Biobank Days' could even be organized on a national level to increase impact.



2 Aims and Strategy for Public Outreach

Public outreach activities can serve to provide an introductory level understanding of biobanking and a broad overview of the manifold applications of biobanks. Communication towards the general public takes place at two levels - cognitive and affective. The cognitive goal is reached when, by the end of an event, visitors are able to understand and recount the role of biobanks in science and society, and differentiate between misconceptions and justified considerations. The affective goal is reached when participants gain trust in, and a positive attitude towards, biobanks and biobank-enabled research after attending an event.

The main goals:

- raising awareness of biobanks among the general public
- informing the general public about biobanks (*cognitive level*)
- addressing the worries of the public about biobanking (*cognitive level*)
- generating a positive attitude towards biobanks by conveying the value of biobanking and research for science and society (*affective level*)
- communication, in a uniform nation-wide way, different aspects of biobanking such as:
 - ethical, legal and societal issues (ELSI)
 - informed consent (vs. opt-out, future law WzI)
 - self-initiated donation
 - donor/patient/citizen participation, e.g. similar to the Maatschappelijke Adviesraad Biobankonderzoek (MAB; Patient & Public Advisory Council)
- promoting biobanken.nl as an information source
- showcasing the collaborative efforts of biobanks and biobank research - for example, in the context of BBMRI.nl

Strategy to achieve the goals

The following infoboxes on [p. 4](#) and [5](#) summarize practical tips on how to engage with visitors during a Biobank Day to achieve the main goals.



HOW TO CONVEY KNOWLEDGE: 5 PRINCIPLES BY MERRILL (2002)

The basis for conveying knowledge is to adapt the language to your audience. Use simple and accessible language and avoid difficult terminology.

1. Engage visitors in solving real-world problems

Inform visitors to a Biobank Day about the far-reaching possibilities of biobanking - how it contributes to biomedical research and consequently to solving health problems. In that way, visitors understand how they can contribute. Explain that donating biomaterial and data to biobanks is a way of actively supporting research into diseases such as cancer or hereditary diseases such as cystic fibrosis, and therefore contributes to solving real-world problems.

2. Activate existing knowledge

Activate visitors' existing knowledge and connect it to biobanks. For example, some adults will remember from school that 'the code of life' is DNA and that some diseases are caused by mutations in a person's DNA. The connection to looking at the DNA in blood or tissue samples to link particular mutations to specific diseases is therefore logical. However, some visitors, especially children, will be unfamiliar with biological terms such as DNA. In that case, adopt a more basic-level approach, linking their pre-knowledge that many diseases can be treated with medicines to the fact that biobanks help researchers to develop new medicines. Any connection to existing knowledge deepens the learning experience.

3. Demonstrate new knowledge

Demonstrate new knowledge by providing examples or using visualizations and demonstrations. Interactive demonstrations and experiences deepen the learning experience. For example, by conducting a guided tour through a biobank you can illustrate the process from sample collection and sample preparation through to storage in freezers, and the subsequent process of preparing samples ready for researchers to examine them under microscopes or extract DNA. By physically showing people what goes on, new knowledge gets better internalized. Construct 'hands-on' activities such as games, for example, pipetting red-stained water that resembles blood samples and then properly labelling and storing them, to deepen the learning experience.

4. Let the visitor apply new knowledge

Let visitors voice their new knowledge. For example, incorporate a quiz to let visitors test their newly-acquired knowledge about biobanks and be rewarded with a prize. Alternatively, in one-on-one discussions, ask them to explain the concept of biobanks or compare common misconceptions with their own conceptions, then offer appropriate feedback. The application of new knowledge will reinforce the learning experience.



5. Integrate new knowledge into their world

Let visitors publicly demonstrate their new knowledge about biobanks by reflecting, discussing and defending their own views with others. In that way, new knowledge gets integrated into their world.

HOW TO CONVEY A POSITIVE ATTITUDE

Attitude formation is highly dependent on personal knowledge, experiences, views and beliefs.

1. Base attitude formation on acquired knowledge and created experiences

When conveying knowledge about biobanks, visitors gain new experiences during the learning process. For example, during a guided tour through a biobank, they can see how carefully the biobanking process is organized and handled, and how specific steps in the process guarantee the protection of personal data. This type of learning process, combined with experiences it offers, can be the first step in forming a positive attitude towards biobanks.

2. Consider and respect a visitor's beliefs and values

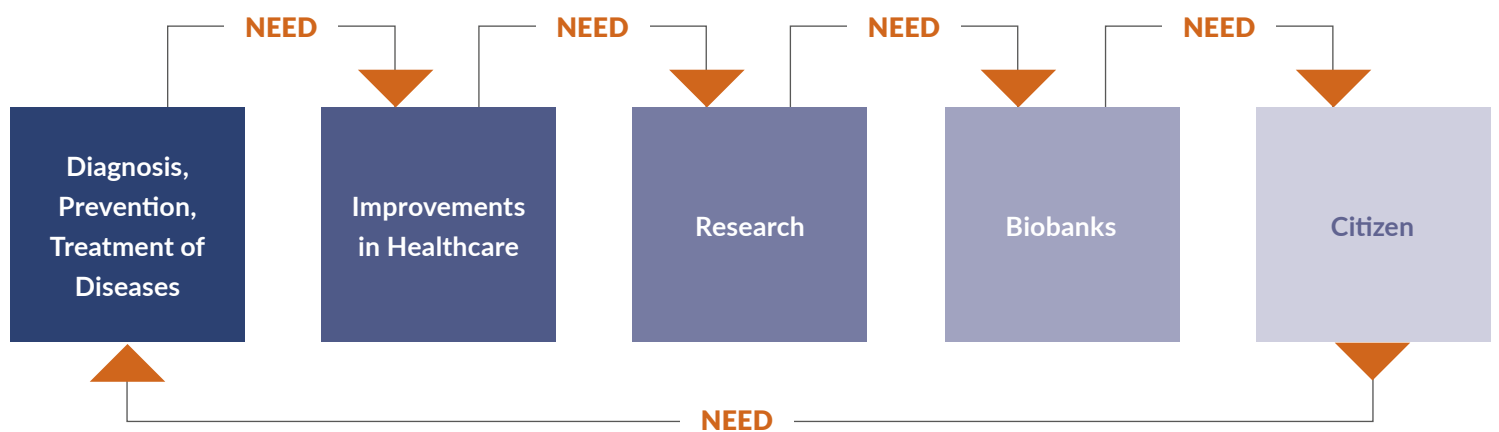
Personal factors, such as religion or a (family) history of disease, must be considered in the attitude formation process. Since open dialogues can quickly and easily touch on personal issues, these issues need to be handled in a sensitive, respectful, and accepting way. Do not argue with visitors about sensitive issues. The purpose of an interactive biobank open day is to elucidate the benefits and importance of biobanking to visitors without imposing any one opinion. Visitors should remain independent in their attitude formation.

3. Evoke empathy and emotions

In attitude formation, the persuasive power of emotions can be very effective. For example, a presentation in which a guest speaker shares their personal experiences of how a biobank helped them to overcome a disease can be a powerful tool. Active members of an appropriate Patient Council are often good choices. However, this approach does not work for every type of visitor.

3 Communication Messages

Rather than starting an event by explaining what a biobank is, try a reverse approach that builds up a 2-way conversation. For example, as illustrated below, start by making a statement that every visitor will almost certainly agree with such as 'so we can all enjoy life to the full, diseases need to be diagnosed, treated and prevented'.



Why not making a story out of it?

Nina has COVID-19 and needs to be treated in hospital.

As soon as she gets to hospital, many different tests are done and blood samples are taken.

Nina is approached by her doctor and asked if she would give consent for her blood and her medical data to be used in research to find a cure or a vaccine for COVID-19 that could help future patients.

Before making her decision, Nina needs a bit more explanation from her doctor:

“Your body material and your data would be stored in a biobank. Researchers would use this stored material and your medical data, as well as those of other patients, in experiments to answer scientific questions. The outcomes of these studies may help to improve the treatment of COVID-19 or find a way to prevent the disease by developing a vaccine. Without this kind of research, no vaccine or treatment for COVID-19 will be found.”

Nina thinks this sounds very useful, but she is worried about what exactly will happen with her data. Her doctor explains:



“Biobanks and researchers take a lot of measures and precautions to ensure that your data is handled in a safe, protected, relevant and responsible way. For example, before being used in research, your data is always anonymized and encrypted, which means it cannot be traced back to you. Moreover, all research projects are reviewed and approved by an ethics committee, and there are laws and regulations in place to secure the whole procedure. You don’t need to worry that your data will be shared insecurely, and it definitely will not be sold to third parties.”

With that explanation, Nina is reassured and gives her consent. She is happy that she will actively contribute to research into COVID-19 that could find a vaccine or treatment in the future. Finally, her doctor says:

“If you’re interested, **check out [biobanken.nl](https://www.biobanken.nl).** It’s a new website where all aspects of biobanking are thoroughly explained. You can even post questions that will be answered online. But you can also always get in touch with your general practitioner or hospital doctor to ask questions or express your concerns. Maybe you could tell your friends and family about your experience or even join a Patient Council (MAB) if you feel strongly about things. Either way, I know it’s an intricate issue but let me assure you: **as doctors, researchers and biobankers, we are always open to discuss how we can best facilitate biomedical research while protecting the privacy of our biobank donors. Let’s start a conversation to together do common good for society.**”

Not everyone can be persuaded so easily of course. However, this example represents how basic information that includes the core concepts or ‘take-home-messages’ about biobanking can be conveyed to the public.



4 The right setup and content

A Biobank event in form of an open day or as part of a science festival is an ideal opportunity to connect biobanks directly with the public. This type of event allows you to produce educational material in formats that appeal to various age groups, education levels, ethnicities and interests (Wharton and Rutherford, 2011). However, this multifaceted target audience poses special challenges that need to be considered at a public outreach event. The main group of visitors to science festivals comprises families who are motivated to attend either because of theme identity (visitors attend based on the topic and the opportunity to learn something new) or the fun and entertainment factor of the event (Idema and Patrick, 2019). Families are diverse and inter-generational groups. It is therefore crucial to design the event in a way that it appeals to all visitors. There are seven points to consider when designing a successful open day or science festival.

GUIDELINES FOR A SUCCESSFUL EVENT

7 points to consider when planning your event (Idema and Patrick, 2019)

1. Immersion

In order to develop ownership of experiences and create science content knowledge, visitors need to be immersed in an activity.

2. Active Participation

When visitors are cognitively and meaningfully involved with the materials, active participation in learning occurs. By being involved through analyzing, synthesizing or evaluating information, visitors are fully engaged with the subject and have a deeper learning experience. The actions involved in the activity must therefore relate to the concepts being conveyed.

3. Focus

The activity needs to focus on the topic in order to evoke visitor motivation to participate in the activity.



4. Play

Including hands-on interactions and the freedom to make choices in activities stimulates play, which fosters the discovery of new information. This interactivity is central to learning in children. Learning activities that include play allow the participant to better understand connections between cause and effect and are therefore more meaningful.

5. Facilitator/Guidance

Informal educators and staff facilitate interactions and learning and are therefore an important factor in the learning process. All activities need guidance, and staff needs to be present to help with questions about information material or facilitate content-related discussions.

6. Connections to Local Community/Knowledge

The design of an activity needs to be based on the way learners think about the topic and the value they place on informal experiences. The audience, its prior knowledge about the topic, and the physical surroundings therefore need to be considered by informal educators when designing an activity. The personal beliefs and views of the visitors will influence how they assimilate new knowledge.

7. Inclusion

In a successful design, the activities should either be accessible to all visitors, or should focus on a specific group of visitors - for example, children or adults. To incorporate different levels of understanding, play activities can be designed for children, while the focus for adults could be on information material.

Personal experiences of biobank representatives active in public outreach showed that even though activities were targeted at children, the activities were often enjoyed equally by adults. It appears that adults also like to get information in a simple, playful and understandable way especially when experiencing an activity together with their children. Activities designed for children could therefore also be useful for adults.



4.1 HOW TO REACH YOUR AUDIENCE

You could organize an interactive biobank day as part of an existing science festival such as the *Netherlands weekend van de wetenschap*. The publicity around a well-known festival helps to reach a wider audience. Participation may depend on whether the institution your biobank belongs to participates in the *weekend van de wetenschap*, because it can be difficult for a biobank to participate independently. If the parent institution your biobank belongs to has been asked to focus on a specific non-biobank related topic, that could equally prevent your participation.

You could, of course, organize your own interactive day independently. A more low-key possibility would be to focus on the network within your own hospital or institution. Setting up an interactive outreach event for colleagues and their family members could allow you to test an outreach plan and materials and act as a pilot for a large-scale public outreach event at a later date. It would almost certainly strengthen internal communication within your institute.

For a more extended version of an interactive biobank day, you could invite people for an off-line interactive public outreach event. For example, you could invite people already registered in your cohort, while also asking others to register and participate. This was successfully done by hersenonderzoek.nl. At their pilot-event, people were asked to donate a blood sample, with the number of people offering to do so exceeding their sample collection capacity.

The most ambitious initiative is organizing an interactive day for the general public, in which case the most important thing is to advertise your event effectively. A publicity campaign should be started as soon as a date for the event is set.

To reach as many people as possible, you can use multiple tools and channels:

- news items on websites and in newsletters
- a short invitation video containing the most important information and presented in an informal personal way. For example, the [teaser video for the 2019 Weekend van de wetenschap](#)
- social media posts
- interviews or short reports involving biobank staff, volunteers or patients in local newspapers or on local radio and TV channels
- prints/posters in your area e.g. at bus stations
- flyers and stickers from your institution - for example, adding a flyer to all letters to your patients

A broad advertising campaign that uses multiple tools/channels will attract a wider and more engaged audience, with the result that an independently organized biobank day can be as effective as a general event such as the *weekend van de wetenschap*.

4.2 INFORMATION MATERIAL AND ACTIVITIES

To reflect the different time, staff and funding resources available to biobank institutions, we have designed several activities requiring various levels of effort. In the following list, you will find a description of each activity, how much effort is needed to set it up, what kind of materials are needed, and which points in the **7-step Guideline for a Successful Event** the activity fulfills. You are advised to choose the program that best fits with your biobank event. It should be emphasized that for a public outreach event to be interesting for visitors not all the listed activities are necessary. However, we recommend a 'basic set', comprising having a stand, showing a video, handing out flyers, and possibly organizing a quiz, is needed to outreach in a meaningful way. The promotion of events, for example, in local press or on social media is also a valuable action.

Information Material

- information flyer to take home
- information flyer for kids: paper/booklet including games/quizzes
For inspiration see Chapter 8 on biobanking in this [Dutch booklet for children about medical scientific research](#) or this [YOUth Got the Power](#) photo story booklet informing children about longitudinal research
- the [Biobank video](#), originally from Erasmus MC.

Activities for adults

Guided tour through a biobank

- Ticks these points for a successful event: 1, 2, 3, 5, 6, 7



“The tour should include the laboratories, freezers, the pathology department and especially the liquid nitrogen tanks - because they are always a winner!”

Hilde Brouwers (Erasmus MC), Photo by Ruud Koppenol



“A guided tour for children is very interesting. If the tour is suitable for children, it will probably be interesting for parents as well.”

Marije Witsenboer (YOUth)

Presentations by researchers and doctors sharing their relation to biobanks and talking about successful research projects

- Ticks these points for a successful event: 1, 3, 5, 6, 7

A talk by a guest speaker sharing their personal experience with biobanks (e.g. a member of the MAB)

- Ticks these points for a successful event: 1, 3, 5, 6, 7



TIP: This could be particularly useful if you want to reach out to specific (ethnic) subgroups. Involving representatives of particular communities (local ambassadors) and letting them share their experience with biobanking can be a powerful tool to reach a specific target group.

'On the spot donation'

This was performed by herseonderzoek.nl, which invited volunteers to directly donate samples at the event. Note, however, that this requires intensive planning to comply with biobanking regulations.

TIP: If your institute is not equipped for self-initiated donations yet, you can refer interested visitors to existing population biobanks.

Activities for children

Coloring pictures (see [appendix](#))

- Effort: low
- Required materials: coloring-picture printouts of biobank/science motifs, crayons. Optional: a prize for the best coloring (e.g. a small stuffed animal/science book)
- Description: Activity for younger children. Children can either color the printouts and take them home or they can leave their name, age and the e-mail address of an accompanying adult, after which their picture is placed on a picture wall on the biobank stand. At the end of the day, a winner is chosen and contacted via e-mail. The prize can then be sent to the winner.
- Ticks these points for a successful event: 1, 2, 3, 4, 5, 7

Quiz (See the example in the [appendix](#) as .ppt and .jpg version)

- Effort: medium
- Required materials: laptop, screen, quiz in the form of a PowerPoint file and/or a paper-based multiple-choice answer sheet, pens, small presents such as a frisbee, yoyo, button, stickers.
- Description: Children (and accompanying adults) are asked basic questions about biobanking and research by a staff member or can complete a quiz on paper on their own. Children get a small present after finishing the quiz.
- Ticks these points for a successful event: 1, 2, 3, 5, 6, 7

Pipetting game

- Effort: medium
- Required materials: falcon tubes or recognizable blood collection tubes filled with red-stained water to represent blood samples, Eppendorf tubes, simple pipettes
- Optional: stickers that represent barcodes
- Description: Children can practice pipetting by sampling fake 'blood' from a bigger falcon tube into small Eppendorf tubes. Optional: the Eppendorf tubes can be labeled with stickers that represent barcodes and



shown to be properly stored in an example freezer or cupboard.

- Ticks these points for a successful event: 1, 2, 3, 4, 5, 7

Biobank donor game (*originating idea from Radboud UMC*)

- Effort: high
- Required materials: biobank quiz, tubes with chocolate, consent forms, pens, ice cream
- Description: children do a quiz about biobanks and are rewarded with a 'blood tube' filled with red chocolate drops, representing a blood sample. The children then receive information about the principle of biobanks and are asked whether they want to donate their chocolate blood sample to a biobank. If the children decide to donate, they need to fill out a consent form, after which they get rewarded with ice cream from the freezer.
- Ticks these points for a successful event: 1, 2, 3, 4, 5, 6, 7

Peggy Manders, Radboud UMC: "We let children take a quiz to teach them about biobanking in a playful way. In this way, the parents are also informed. Last year we 'issued' almost 250 ice creams and 'blood tubes'."

Microscope demonstration

- Effort: high
- Required materials: simple microscope, biological samples
- Optional: microscope projection screen
- Description: Under careful supervision by a staff member, children (and adults) can look at biological samples such as blood smears under the microscope. Optional: The microscope image can be projected onto a big screen, so more people can enjoy the experience.
- Ticks these points for a successful event: 1, 2, 3, 5, 6, 7

'Children's college' live and online

- Effort: high
- Required materials: screen, microphone, camera
- Description: A biobank representative explains how a biobank works and answers children's questions. This can be performed live as a lecture and optionally streamed online. The recording could be made available for other biobanks.
- Ticks these points for a successful event: 1, 2, 3, 5, 6, 7

Marije Witsenboer (YOUth) refers to the successful example where the UU Wetenschapsknooppunt did this through a YouTube Live Stream: (<https://www.uu.nl/wetenschapsknooppunt/streamtheprofessor>).



5 Biobank Glossary

A brief overview and explanation of terms relevant for biobanking. These definitions will help you to communicate in a uniform way about these terms, which is one goal of a national public outreach event. A more extensive and Dutch language glossary can be found on www.biobanken.nl/woordenlijst.

Biobank A biobank is a collection of biological material and medical data. Biological samples (for example, blood, tissue or urine) are stored in freezers or paraffin blocks to last over long periods of time (> 10 years). Medical data is stored in databases. There are many different types of biobank, which can mostly be divided into ‘further use’ (nader gebruik) or *de novo*. Body materials, for example, those taken during surgery, blood sampling or joint aspiration, are stored in the hospital. Data is stored in a patient file. If a doctor wants to check something later, the patient does not have to donate material again. This material is also used to validate diagnostic analyzers. Such a biobank is called a ‘further use biobank’ or a pathology biobank. A *de novo* (Latin for ‘new’) biobank is a clinical or population biobank in which targeted materials are collected for a specific study. Sometimes a hospital, researcher or patient organization starts a whole new biobank for doing medical research in a specific area or a limited research question, for instance a specific disease. This is then a clinical biobank. A population biobank collects material and data to conduct a long-term study of a large group of people (population). These studies monitor the health of a population over a period of 10 or more years. The studies often focus on differences between people in terms of lifestyle and psychological and social characteristics.

Biomedical research Biomedical research can be conducted using biological material and medical data to examine the causes, diagnosis, prevention and treatment of diseases. Researchers can use biological material and medical data stored in biobanks to conduct experiments. Most research proposals need to be pre-approved by an ethics committee and material and data from biobanks is always encrypted or anonymized in order to protect the privacy of the biobank donor.

Consent, opt-out regulation and the WzI Participants are asked for **consent** (permission) in order to have their samples and data stored in a biobank and used for research. A consent form with all the required information about the storage and possible research must be signed by the participant. Consent can be limited or withdrawn at any time without stating a reason. This has the consequences that no material and data (or a part of it) will be used in future research



and the donor's samples and data will be eliminated from the biobank. However, this cannot be done retroactively for research that has already been conducted.

The **opt-out regulation** is an alternative approach to consent. Biological material and data gets stored and used for research until the donor formally expresses a wish for this not to be done. In that case, they can 'opt-out' which is the equivalent of withdrawing consent. The opt-out regulation simplifies the situation for biobanks and researchers when gathering material and data.

However, a future law '*Wet zeggenschap lichaamsmateriaal*' (**WzI**), currently being planned, will determine that material and data can only be stored and used for research purposes if the donor has actively given consent (with exceptions).

ELSI Ethical, legal and social implications associated with research, in this case in relation to biobanking. Potential biobank donors can be advised about ELSI via [Biobanken.nl](https://www.biobanken.nl).

**encrypted/
pseudonymized vs.
anonymized data**

With **anonymizing**, personal data is copied to a data set in such a way that it can no longer be traced back to the donor. To do this, all directly identifiable elements of a donor's personal data are removed, for example, name, address etc.

Pseudonymization also removes identifiable elements of a donor's data but replaces them by one or more artificial identifiers (pseudonyms). The pseudonymized dataset and the security key linking the pseudonyms to the source data are held separately and safeguards are put in place to prevent re-identification (e.g. policy or contracts). It is important that the original identifying elements, or the source data, are still present. When the source data is destroyed, or re-identification is otherwise impossible, pseudonymized data becomes anonymous data.

**Unsolicited or
Incidental findings**

An incidental finding is a finding that was not searched for in the research, but which may be important for the health of a person and their descendants. For example, a hereditary anomaly in their DNA that significantly increases their or their offspring's chance of contracting a specific disease in the future. Sometimes early treatment is helpful. It is then obvious that this person (via their general practitioner or treating specialist) should be informed of the finding. If participants are asked for permission to use their body material for (biobank) research, in most cases they can also decide whether they want to be informed about relevant incidental findings or not.

Privacy

Privacy defines the boundary around individuals or groups within which they cannot be spied on or influenced. Privacy means that an individual can do things without the outside world knowing about it, interfering with it, or influencing it. The protection from influence, or in other words the right to be left alone, is one of the universal human rights.



Residual material Residual material is body material that no longer needs to be used for the diagnosis or treatment of a patient and could therefore be used for research.

Self-initiated donation Self-initiated donation is the active and voluntary donation of biomaterial and data to a biobank, independently of the medically required procedures during which biomaterial and data is usually obtained. Self-initiated donations are the basis of population biobanks and represent a large resource for other biobanks and research. However, most biobanks do not have the facilities to support self-initiated donations yet.



6 References

- Biobanken Nederland (2020) *Veelgestelde vragen over biobankonderzoek*. Available at: <https://www.biobanken.nl/veelgestelde-vragen-over-biobankonderzoek> (Accessed: 14 February 2020).
- Merrill, M. D. (2002) 'First principles of instruction', *Educational Technology Research and Development*, 50(3), pp. 43-59. doi: 10.1007/bf02505024.
- Wharton, J., & Rutherford, E. H. (2011). Connecting ocean science and communities through public science events. *Currents, the Journal of Marine Education*, 27, 11-15.
- Merrill, M. D. (2002). First principles of instruction. *Educational technology research and development*, 50(3), 43-59.
- Giamellaro, M. (2014). Primary contextualization of science learning through immersion in content-rich settings. *International Journal of Science Education*, 36(17), 2848-2871.
- Ballantyne, R., Packer, J., & Falk, J. (2011). Visitors' learning for environmental sustainability: Testing short-and long-term impacts of wildlife tourism experiences using structural equation modelling. *Tourism management*, 32(6), 1243-1252.
- Bonwell, C. C., & Eison, J. A. (1991). *Active Learning: Creating Excitement in the Classroom*. 1991 ASHE-ERIC Higher Education Reports. ERIC Clearinghouse on Higher Education, The George Washington University, One Dupont Circle, Suite 630, Washington, DC 20036-1183.
- Roussou, M. (2004). Learning by doing and learning through play: an exploration of interactivity in virtual environments for children. *Computers in Entertainment (CIE)*, 2(1), 10-10.
- Andre, L., Durksen, T., & Volman, M. L. (2017). Museums as avenues of learning for children: A decade of research. *Learning Environments Research*, 20(1), 47-76.
- Crowley, K., & Brahm, L. (2016). Learning to Make in the Museum: The Role of Maker Educators. In *Makeology* (pp. 29-43). Routledge.
- Schauble, L., Gleason, M., Lehrer, R., Bartlett, K., Petrosino, A., Allen, A., & Street, J. (2002). Supporting science learning in museums. *Learning conversations in museums*, 425, 452.
- Zimmerman, H. T., & Weible, J. L. (2017). Learning in and about rural places: Connections and tensions between students' everyday experiences and environmental quality issues in their community. *Cultural Studies of Science Education*, 12(1), 7-31.