

## PLAN OVERVIEW

*A Data Management Plan created using DMPonline*

**Title:** HEMGEN: Health, European Muslims and Gender: Medical Authority and Assisted Reproductive Technologies in Sunni Islam

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**Project abstract:**

Infertility is estimated to affect an average of 14% people worldwide. It is an issue that affects equally both men and women, although it is often associated with a women's social burden and the case of Islam is not an exception. While religion influences Muslims' health beliefs, behaviours and decisions, health providers are not always aware of cultural and religious preferences and norms. Thus, Islamic norms on health treatments can result in Muslim's exclusion from the health care system, especially affecting Muslim women. This can especially impact issues on infertility and reproduction, which holds exceptional moral and social significance across religions.

Through an innovative focus, this project aims to advance scientific knowledge about how Sunni Muslims in a minority context in Europe navigate between the authority of medical science and the authority of religion, and to what extent this affects their access to health care. The project will provide empirical data and develop a theoretical framework based on gender studies, sociology of religion and anthropology of health literatures. This will be achieved by applying intersectional perspective and qualitative methodologies, consisting of semi-structured interviews with Health Professionals and Muslims who have had fertility treatments.

The research will be conducted in two European cities: Oslo and Barcelona. Both cities have experienced a rapid increase in religious diversity in last decades but are different in their organisation of religious communities and of health systems. The comparison between the two cities will provide insights into differences among Sunni Muslims around negotiating health, religious and gender issues. This project will contribute to new avenues of investigation concerning the life conditions of Sunni Muslims in Europe and will develop new knowledge on health inequality that may be adapted for future research on other religious minorities or vulnerable groups.

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# HEMGEN: HEALTH, EUROPEAN MUSLIMS AND GENDER: MEDICAL AUTHORITY AND ASSISTED REPRODUCTIVE TECHNOLOGIES IN SUNNI ISLAM

## DATA SUMMARY

### Will you re-use any existing data and what will you re-use it for?

The project will create new empirical data and will not re-use any existing data.

### What types and formats of data will the project generate or re-use?

The project will generate qualitative data based on interviews.  
The project will also generate a list of codes for analysis.

### What is the purpose of the data generation or re-use and its relation to the objectives of the project?

The project will imply the conduction of interviews with Muslim participants, Health Professionals and Key Informants in order to get first-hand qualitative information about their experiences and perspectives on the negotiation between authority of medical science and authority of religion. It is important to do these interviews as there are no previous data on this specific topic and the focus is on the contemporary experiences of people dealing with these issues.

### What is the expected size of the data that you intend to generate or re-use?

I will generate transcripts from interviews, at least 60 interviews.

### What is the origin/provenance of the data, either generated or re-used?

The origin of the data will be interviews.

### To whom might your data be useful ('data utility'), outside your project?

The empirical results can be useful for other researchers working on similar topics, as well as policy makers and health professionals. However, only anonymized data will be published.  
The list of codes for the analysis can be shared, and this can also be useful for researchers working on similar topics.

## FAIR DATA

### 2.1. Making data findable, including provisions for metadata: Will data be identified by a persistent identifier?

The list of codes for the analysis will be easily identified in a suitable data repository (to be confirmed).

### 2.1. Making data findable, including provisions for metadata: Will rich metadata be provided to allow discovery? What metadata will be created? What disciplinary or general standards will be followed? In case metadata standards do not exist in your discipline, please outline what type of metadata will be created and how.

The metadata that will be included will be Title of the codebook, creator's name (ORCID), Title of research project, Funding information, Geographic scope, Time period of data collection and keywords.

**2.1. Making data findable, including provisions for metadata: Will search keywords be provided in the metadata to optimize the possibility for discovery and then potential re-use?**

Yes, a list of 5-7 keywords will be provided in order to easily identify the relevance of the project to other researchers.

**2.1. Making data findable, including provisions for metadata: Will metadata be offered in such a way that it can be harvested and indexed?**

The list of codes for the analysis will be easily identified in a suitable data repository (to be confirmed)

**2.2. Making data accessible - Repository: Will the data be deposited in a trusted repository?**

Due to privacy reasons, data will be stored in TSD during the project and then deleted after the end of it. The data which can be shared will be deposited in a trusted repository (to be confirmed)

**2.2. Making data accessible - Repository: Have you explored appropriate arrangements with the identified repository where your data will be deposited?**

Personal data will be stored in TSD, and it will be deleted after the project finishes (August 2027).

**2.2. Making data accessible - Repository: Does the repository ensure that the data is assigned an identifier? Will the repository resolve the identifier to a digital object?**

I will prioritize using a repository that ensures that the data is assigned an identifier, in order to make it accessible.

**2.2. Making data accessible - Data:**

**Will all data be made openly available? If certain datasets cannot be shared (or need to be shared under restricted access conditions), explain why, clearly separating legal and contractual reasons from intentional restrictions. Note that in multi-beneficiary projects it is also possible for specific beneficiaries to keep their data closed if opening their data goes against their legitimate interests or other constraints as per the Grant Agreement.**

Personal data and interview transcripts will not be shared as they have sensitive and personal data. The only data which can be re-used are codes of analysis.

**If an embargo is applied to give time to publish or seek protection of the intellectual property (e.g. patents), specify why and how long this will apply, bearing in mind that research data should be made available as soon as possible.**

Not applicable for this project

**Will the data be accessible through a free and standardized access protocol?**

Not applicable for this project

**If there are restrictions on use, how will access be provided to the data, both during and after the end of the project?**

Not applicable for this project

**How will the identity of the person accessing the data be ascertained?**

Not applicable for this project

**Is there a need for a data access committee (e.g. to evaluate/approve access requests to personal/sensitive data)?**

Not applicable for this project

**Will metadata be made openly available and licenced under a public domain dedication CC0, as per the Grant Agreement? If not, please clarify why. Will metadata contain information to enable the user to access the data?**

The data that will be openly available will have a public domain using a data repository, without the need to ask for permission. It will also be available in the project's website.

**How long will the data remain available and findable? Will metadata be guaranteed to remain available after data is no longer available?**

The data will be available with no limits.

**Will documentation or reference about any software be needed to access or read the data be included? Will it be possible to include the relevant software (e.g. in open source code)?**

The data won't require a specific software.

### **2.3. Making data interoperable:**

**What data and metadata vocabularies, standards, formats or methodologies will you follow to make your data interoperable to allow data exchange and re-use within and across disciplines? Will you follow community-endorsed interoperability best practices? Which ones?**

The data will be shared with keywords.

**In case it is unavoidable that you use uncommon or generate project specific ontologies or vocabularies, will you provide mappings to more commonly used ontologies? Will you openly publish the generated ontologies or vocabularies to allow reusing, refining or extending them?**

The list of codes will be shared using a wide open format such as .pdf

**Will your data include qualified references[1] to other data (e.g. other data from your project, or datasets from previous research)?**

Once a repository is identified, I will identify possible qualified and datasets from other projects which can be related.

### **2.4. Increase data re-use:**

**How will you provide documentation needed to validate data analysis and facilitate data re-use (e.g. readme files with information on methodology, codebooks, data cleaning, analyses, variable definitions, units of measurement, etc.)?**

I can facilitate data on information on methodology and codebooks, which can be easily downloaded in the project's webpage and in the repository (to be confirmed).

**Will your data be made freely available in the public domain to permit the widest re-use possible? Will your data be licensed using standard reuse licenses, in line with the obligations set out in the Grant Agreement?**

The codebook will be widely available through the project's website, as well as open repositories.

**Will the data produced in the project be useable by third parties, in particular after the end of the project?**  
Only codebooks could be used after the end of the project.

**Will the provenance of the data be thoroughly documented using the appropriate standards?**

The data will be shared using appropriate standards and appropriate open repository.

**Describe all relevant data quality assurance processes.**

The data will be shared with specific information about methodology and ethical protocols.

**Further to the FAIR principles, DMPs should also address research outputs other than data, and should carefully consider aspects related to the allocation of resources, data security and ethical aspects.**

Participants will be requested to have consent for processing their data for the project's analysis, but their personal information will be deleted after the project's end.

The identity of the participants will be protected using anonymization and the data will be deleted at the end of the project.

All the personal data will be store in secured program (TSD). The only data which will be openly available are codes for analysis.

**OTHER RESEARCH OUTPUTS**

**In addition to the management of data, beneficiaries should also consider and plan for the management of other research outputs that may be generated or re-used throughout their projects. Such outputs can be either digital (e.g. software, workflows, protocols, models, etc.) or physical (e.g. new materials, antibodies, reagents, samples, etc.).**

Another possible research output can be a protocol explaining the methodology and the ethical process of the project, which can be useful for other researchers working in similar topics.

**Beneficiaries should consider which of the questions pertaining to FAIR data above, can apply to the management of other research outputs, and should strive to provide sufficient detail on how their research outputs will be managed and shared, or made available for re-use, in line with the FAIR principles.**

Research outputs will be openly available in specific repositories and on the project's website.

**ALLOCATION OF RESOURCES**

**What will the costs be for making data or other research outputs FAIR in your project (e.g. direct and indirect costs related to storage, archiving, re-use, security, etc.)?**

There might be cost related to the repository in which to share the codebooks.

**How will these be covered? Note that costs related to research data/output management are eligible as part of the Horizon Europe grant (if compliant with the Grant Agreement conditions)**

The cost will be covered by the institution (OsloMet) of with the project's budget (if necessary)

**Who will be responsible for data management in your project?**

The main researcher - Rosa Martinez-Cuadros- will be responsible for the data management and all the related activities: data capture, data quality, storage and back up and data archiving.

**How will long term preservation be ensured? Discuss the necessary resources to accomplish this (costs and potential value, who decides and how, what data will be kept and for how long)?**

The personal data will only be stored during the project's duration. The open resources available will be accessed with no limit.

**Data security**

**What provisions are or will be in place for data security (including data recovery as well as secure storage/archiving and transfer of sensitive data)?**

The data will be stored in the secured program TSD, provided by the OsloMet University. This program allows to collect, store and analyse sensitive data in a secure environment: with two-factor identification, password log in, and not connected to internet. It also provides integrated solution for collecting sensitive data (Nettskjema) and it offers safe transfer from specific app for recording (Diktafon) which ensure transfer to TSD without using internet and is deleted right after transfer.

The main researcher- Rosa Martinez-Cuadros- will be responsible for back up and will make sure that the data is not stored in risky devices, such as laptops or external storage.

## **ETHICS**

**Are there, or could there be, any ethics or legal issues that can have an impact on data sharing? These can also be discussed in the context of the ethics review. If relevant, include references to ethics deliverables and ethics chapter in the Description of the Action (DoA).**

The research involves interviews with human participants which include sensitive information (about their religion, their ethical background and health information) and this is why this data cannot be shared. Interview transcripts are difficult to anonymise and the participants might potentially be identified through them. Ethical concerns are considered and only anonymous data can be shared. The project has been already assessed by SIKT.

**Will informed consent for data sharing and long term preservation be included in questionnaires dealing with personal data?**

All participants will be given an Information Letter and a Consent Form in order to preserve their personal data. The identity of participants will be anonymized. They are also informed that their data will not be shared outside the researchers involved in the project.

## **OTHER ISSUES**

**Do you, or will you, make use of other national/funder/sectorial/departmental procedures for data management? If yes, which ones (please list and briefly describe them)?**

Not applicable in this project