

Title

**0084**by **Sarah Ahannach** in **Inclusive Health Research 2024****Original Submission**

Score

n/a

## 1. The Entry

1 1. Lead organisation or Institution chiefly responsible for submitting this entry

University of Antwerp

Registered Address

Groenenborgerlaan 171  
Antwerp  
Antwerp  
2020  
BE  
51.1782  
4.41555

Type of Organisation

Academic/research institution

Website URL

<https://isala.be/en/>

1.3 Name of project or programme

The Isala Sisterhood

1.4 Date that the project or programme began

24th of March, 2020

1.5 Countries in which research / implementation was undertaken

Belgium  
Cameroon  
Canada  
Colombia  
Estonia  
France  
India  
Italy  
Madagascar  
Morocco  
Peru  
South Africa  
Spain  
Switzerland  
Uganda  
United Kingdom  
United States  
Germany  
Venezuela  
Nigeria

1.6 About partners and collaborators

Here you should name up to three collaborating organisations and provide a contact email address for each one that you name. We will then send a request for a supporting statement, which will be taken into account in the scoring of this application.

Partner organisation/institution #1

Magaly Marlitz Blas from Mamás del río (Mothers of the river - Universidad Peruana Cayetano Heredia)

Type of Organisation

Academic/research institution

Website URL	<a href="https://mamasdelrio.org/mamas-del-rio-en/">https://mamasdelrio.org/mamas-del-rio-en/</a>
Partner organisation/institution #2	Jo-Ann Passmore from the Mucosal Immunology Group (University of Cape Town)
Type of Organisation	Academic/research institution
Website URL	<a href="https://passmore-lab.org.za/who-we-are/">https://passmore-lab.org.za/who-we-are/</a>
Partner organisation/institution #3	David MacIntyre from Department of Metabolism, Digestion and Reproduction (Imperial College of London)
Type of Organisation	Academic/research institution
Website URL	<a href="https://www.imperial.ac.uk/people/d.macintyre">https://www.imperial.ac.uk/people/d.macintyre</a>
The Case Study	
1.8 The Title of Your Case Study	Writing history with your vaginal microbiome and the Isala Sisterhood
1.9 Simple Summary	Women's health is receiving increased attention, but science is still not filling society's needs when it comes to vaginal health. In the last 40 years, no major breakthroughs have been made to manage bladder and vaginal infections. One way to set a societally relevant research agenda is actively involving citizens in scientific dialogues. We founded Isala as a citizen-science project to significantly advance research, diagnostics, and therapeutics for the vaginal microbiome. Isala expanded internationally with a Sisterhood in 20 countries increasing representation in microbiome research. In a co-creative way, more than 6000 women provided intimate samples and data; proposed research objectives; disseminated and interpreted results. Since then, the number of participating women is expanding across the world. Jointly, we break taboos on women's health, increase scientific literacy and provide new insights into the vaginal microbial ecosystem. Together, we are building the largest citizen-science project in the world on vaginal health.
1.10 Introduction	As the principal investigator of Isala, I manage a large and multidisciplinary team ( <a href="https://isala.be/en/about/">https://isala.be/en/about/</a> ) that includes microbiologists, biomedical scientists (dr. Sarah Ahannach, dr. Sandra Condori, Maria Pinedo Bardales), bioinformaticians (dr. Stijn Wittouck, dr. Monica Tcilla, Tim Van Rillaer), biostatisticians (dr. Thies Gehrmann, Kato Michiels), bioscience engineers (Jelle Dillen, Leonore Vander Donck, Isabel Erreygers, Inas Rahou, Caroline Dricot, Maline Victor, dr. Camille Allonsius) and lab technicians (Nele Van de Vliet, Reine Audenaert, Sam Bakelants) from the University of Antwerp collaborating with multiple parties: sociologists (dr. Caroline Masquillier, dr. Nina Van Eekert), communication experts (Studio Maria, Prof. Charlotte De Backer, Prof. Karolien Poels), policy advisors (Sensoa centre for sexual health, Provincial Institute for Hygiene), gynaecologists (Prof. Gilbert Donders team), general practitioners (Prof. Veronique Verhoeven team), several non-profits, and enthusiastic citizens. Our Isala sisterhood is currently active in 20 countries with in each country a passionate research team that takes the lead for their Isala sister project (named after their own role model). Together we closely monitor societal impact, policy development, valorisation and inclusivity. We often organise focus groups and in-depth interviews to include diverse and vulnerable groups (e.g., Moroccan and Turkish women; women who had abortions; women with lower socio-economic backgrounds).
1.11 Key Words	vaginal microbiome, citizen science, women's health, community outreach, health equity, health-promoting microbes, value co-creation, taboo breaking, women empowerment, capacity building
Which category best fits this project or programme?	Addressing a specific unmet health need
2. Unmet Health Need Case Study	These will typically fall in to one of three groups: Group 1: Understanding needs and context Group 2: Designing and conducting research Group 3: Translating research into impact The various suggested sections which follow will not be equally applicable to all groups. We have given an indication of which sections may be most crucial to each but you should use your own discretion and judgement. We are seeking case studies that can be published, so please write your entry assummary, rather than a series of statements addressing the questions. You do not need to repeat information across sections. We do not expect everyone to be able to address all of the questions, as not all will be relevant.

<p>2.1 Who should benefit from the project or programme? (Applicable to groups 1, 2, &amp; 3)</p>	<p>Women's health is receiving increased attention, but science is still not filling society's needs when it comes to vaginal health, beside it affecting half (49.7%) of the global population. For instance, in the last 40 years, no major breakthroughs have been made on managing bladder and vaginal infections such as bacterial vaginosis (BV) that affects around 30% of women globally. The annual global economic burden of treating symptomatic BV in the US alone is already estimated at \$4.8 billion. This US economic burden of BV is nearly tripled when including costs of BV-associated preterm births, HIV cases, fertility issues, etc. Also for fungal infections, about 70% of women worldwide suffer from vulvovaginal candidiasis at least once in their life. An episode of this fungal infection is accompanied by a burning sensation, pain, and reduced mental wellbeing. Due to increasing rates of antimicrobial resistance, the world is in dire need for alternative treatments such as live biotherapeutics (e.g., probiotics with live beneficial microorganisms) and better diagnostics. For example endometriosis diagnosis affecting 1 in 10 women, takes approximately 10 years. Moreover, is there not only a vast lack in therapeutics and diagnostics, the few existing ones are often not translatable to women living in LMICs as most studies have been performed in Western countries. Research has shown that the vaginal microbiome is significantly associated with geographic regions. To bridge the global health equity for vaginal health, the Isala project and its sisterhood was established. Isala is named after the first female doctor in Belgium, Isala Van Diest (1842-1916), who was also an inspiring activist, feminist and role model. The Isala sisterhood consists of 20 inspired citizen-science projects in Belgium, Peru, Switzerland, Cameroon, Morocco, Uganda, Nigeria, France, Spain, UK, USA, Canada, Colombia, Estonia, Germany, India, Italy, Madagascar, South-Africa, and Venezuela, each one named after inspiring women in their own countries. With this sisterhood, we aim to inspire research on women's health and microbiome all over the world while simultaneously helping smaller labs in remote locations with capacity building. The sisterhood researchers stand much closer to their own community while actively participating in stakeholder engagement and community outreach. With the umbrella Isala project, we are creating an ecosystem where research teams in various countries share their best practices (wet lab and in silico research, communication tools, logistics); facilitate international mobility of young researchers; and ultimately support each other in closing the gender data gap.</p>
<p>2.2. Engagement (applicable to groups 1, 2, &amp; 3)</p>	<p>The Isala project was launched in Belgium in March 2020, with no budget for communication and recruitment. The project thus mostly relied on social media, spontaneous press and a lot of volunteering. While aiming for 200 women, within ten days, more than 6000 women registered. Since the Isala citizen scientists are central to the project's scientific and social goals, we went the extra mile to be able to offer them all the opportunity to participate. We collaborate with sociologists to establish their demographic profiles and explore the best options to engage a more diverse and inclusive community in subsequent phases. To inclusify the recruitment of current follow-up projects, we performed focus talks and in-depth interviews with women with a Moroccan and Turkish background (largest ethnic groups in Belgium), as well as women living below poverty levels: we are now implementing the lessons learnt. Additional lessons are picked up from our feedback survey on the science communication, knowledge translation and study set-up which was filled out by more than 2000 citizens. Furthermore, each Isala citizen scientist is empowered to take up the role of an ambassador armed with the necessary communication tools and research updates. We encourage our citizen scientists to spread the news and help us break the taboo on this intimate topic. Besides a vibrant online community (website, recurrent newsletter, blogposts, podcasts, videoclips, webinars, and social media channels), we actively partake in (inter)national offline outreach activities (such as interactive talks, workshops, panel conversations, poster presentations, museum booths, high school education packages, soapbox science, community health kiosks, yearly science and women's days, science festivals (for young and old), museum exhibits, lab tours for children, Isala symposium open for the public, etc.). An exquisite example of the Isala sisterhood were the researchers from the Uganda Isala sister project (Florence) who travelled to the Peruvian Isala sister project (Laura) in the remote Amazon Forest to exchange citizen-science practices with respect to local cultures (<a href="https://isala.be/en/the-isala-sisterhood-lets-write-history-together/">https://isala.be/en/the-isala-sisterhood-lets-write-history-together/</a>). The Isala sisterhood invests a lot in community engagement and building to promote co-creation, build bridges between citizens and scientists, and broaden our perspective. Via these platforms, we daily engage with citizen scientists and enthusiasts. With Isala we create a safe space and kind corner for people to share their story, help each other, co-create interesting research ideas. Overall, with our science communication and community outreach, we estimate to reach approximately 5.000-10.000 people of various ages each month.</p>
<p>2.3. The Research (Particularly relevant for groups 2 &amp; 3)</p>	<p>The Isala project is unique in the microbiome field by taking on a citizen-science strategy to bridge women's health equity gaps and align scientific research with societal needs (<a href="https://isala.be/en/">https://isala.be/en/</a>). This citizen-science approach offers researchers the unique opportunity to facilitate large-scale sampling and data acquisition, while engaging citizens in a co-creative approach that solicits their input on study aims, research design, data gathering and analysis. We aim to guarantee a holistic, community-centred approach that achieves significant societal relevance. Isala and its sisterhood addresses both scientific and societal research questions. Our scientific goals are to map the vaginal microbiome and study its influencing factors to build better diagnostics and therapeutics. All participants received a large survey about demographic, lifestyle and environmental factors via Qualtrics and self-collected vaginal swabs (for microbiome profiling, culturomics and metabolomics). Of note, due to citizens' involvement in the study design additional research questions regarding menstrual hygiene, underwear and diet were included. These were not yet explored in literature and a nice example of co-creation. While our first results were recently published in Nature Microbiology (Lebeer et. al., 2023), we already communicated earlier to the citizen scientists (June 2021). A soon as all data were available, each participant received their personal vaginal microbiome. These first overarching results were also communicated with the broader public (<a href="https://isala.be/en/results/">https://isala.be/en/results/</a>). Our societal goals are to break the taboo on vaginal health, create awareness on intimate research and empower women to take their health into their own hands. We aim to increase scientific literacy by inviting women to our scientific process in microbiology and biotechnology research, and by helping them to critically interpret research results and information on reproductive health. Simultaneously, we highlight women in STEM and actively work with policy makers to deconstruct structural barriers and promote value creation through incentive for behavioural changes towards science and environmental issues. We do this by transparent and recurrent communication, and continuous community outreach activities (giving research a face with many meet-greets both online and offline). These aspects are reflected in each sisterhood project albeit adapted to the local needs, culture and facilities (e.g., lack of electricity in rural areas of Cameroon or the Amazon in Peru). Research teams are also challenged with various logistics aspects. Yet, also activities with sustainable impact on local society were organized such as organizing town halls, educating tribe men and providing women with a safe space to share their story.</p>

2.4. Translating to Impact (Particularly relevant to group 3)	<p>The Isala project is the world's largest citizen science project on women's health studying the female microbiome and its influence on our health and wellbeing. Isala has both fundamental and applied goals, such as finding better diagnostics and therapeutics, but also raising more awareness on vaginal and reproductive health (<a href="https://isala.be/en/">https://isala.be/en/</a>). Isala forms the umbrella for all sister projects sustainable collaborations by practicing Open Science and FAIR principles. In the Isala sisterhood, we believe that in order to advance women's health it is crucial to build capacities in local researchers. The sisterhood is providing a unique opportunity for motivated early-career researchers to start investigating the vaginal microbiome, a research line totally unexplored in their home countries. Up to now, direct beneficiaries of the Isala sisterhood are not only citizens but also young scholars i.e. two Joint-PhD students, one in Laura (Peru), and one in Leke (Cameroon). We have applied for postdoc funding to potentiate the Fatima project (Morocco) among others, and short term trainings in several sisterhood countries. Trained researchers will be able to identify and tackle local health needs. Moreover when starting a sister project, it is advised to also collaborate and interact with key stakeholders by assembling an advisory board. Researchers and key stakeholders interaction is crucial because it is creating conditions for uptaking the knowledge generated in each sister project. For instance in the Laura project members of the advisory board are also members of the Ministry of health, NGOs working in sexual and reproductive health. Another example is the interaction of the Isala daughter project named Luna and the sister projects Laura, Leke and Marie in the recently funded project "The Impact of Menstrual Health Management on the Vaginal Microbiome: Linking Transdisciplinary Health Science and Policy to Improve Safety and Hygiene for the Benefit of Women's Health". In this project, we count with the support of UNFPA-Peru, WHO and UNICEF. Concerning working directly with the society, in the Laura project the results of the vaginal microbiome profile were delivered to the participants in a unique information session where all their doubts were cleared up. In the Leke project, we raised awareness on vaginal health in women and men, who were open to discuss the topic. Finally, we aim to also bring these quality and robust research results (practiced in a standardized way through open and transparent methodology sharing) together to tackle the Sustainable Development Goals for 2030.</p>
2.5. The Future (Applicable to groups 1, 2, & 3.)	<p>Isala is dedicated to breaking the taboo, inspiring and educating women in STEM, informing the general public about women's health and building a vibrant community to support equal rights for all. Isala aims at continuing to advance women's health on a global scale and building capacities on vaginal microbiome research in young researchers from underrepresented countries building equitable global partnerships. Ultimately, our partnership will work together with society to tackle local women's health issues and contributing to closing the healthy equity gap. Isala also aims to push citizen science more to the front of research as it brings citizens closer to science, and science closer to citizens. This provides governments, scientists and policymakers with the opportunity to reflect on societal needs while being open to new forms of research and giving citizens the opportunity to be scientists themselves. Therefore, these different stakeholders not only complement but also challenge each other. Especially for women's health, broadening the social science perspectives, improving protocols and aiming for diverse and inclusive projects could result in large projects that can provide new knowledge on the vaginal microbiome and improve scientific understanding of the general public. To apply citizen science to intimate topics and microbiome projects, the field can benefit from having best practices on data management, (bio)ethics, sampling protocols, inclusive science communication, participant engagement tools, impact assessments, etc. Furthermore, promoting and supporting open science for countries and research teams with less resources and capacity would benefit women all over the world. However, extra efforts and funding are required to not only translate the research results to the public but also to policymakers. Only this way, some of science's and society's grand challenges would be addressed in an open and impactful manner. Moreover, we will encourage a 'non-pink approach' to vaginal and reproductive health since these topics are of importance for people of all genders and ages. For the future, Isala and its sisterhood will further focus on diagnostics, therapeutics, preventive measures and societal impacts. The topics of interests are those where the vaginal microbiome significantly contributes to such as sexual health, vaginal disease prevention, successful fertilization, mental health, overall well-being, healthy pregnancies and newborns, and the immune and microbiome education of newborns, which are all considered key features of a healthy humanity. Therefore, prioritizing research on the vaginal microbiome does not only make sense from a scientific viewpoint but also from a societal one.</p>
4. The Prize Fund	<p>Isala and its sisterhood is constantly evolving and aims to improve its science communication platform. With a strong basis (GDPR and according to Open Science and FAIR), we hope to further professionalize so international researchers and women can use and adapt it for their own societal and scientific needs on reproductive health. It will help us to further inclusify and take away some thresholds that vulnerable groups experience. Together we can create a safe space for women to learn about their own health (scientific literacy), co-create science (citizen-science), and empower them to take their health into their own hands (ownership).</p>
5. Your advice to others	<p>We advise others to adopt an integrative research design and systemic approach to promote new insights in knowledge gaps such as the female microbiome and associated diseases. We promote citizen science as a promising strategy to bridge these gaps and align scientific research with societal needs. A transdisciplinary team and advisory board (e.g., policy makers, academic and industrial researchers, non-profits) incentive innovative research methodologies and scalable scientific results. In addition, making citizen scientists part of the extended research team will create ambassadors for vaginal health and women's wellbeing, and motivate the research team to embark on unique research endeavours.</p>
6. Supporting Evidence	

## 6.1. Funders

Organisation 1:

- Funder: ERC Starting Grant
- Grant title: "Lacto-Be: Advancing Lactobacillus' beneficial potential"
- Award period: 2020-2025
- Value: 1 282 801.57 GBP
- Weblink: <https://cordis.europa.eu/project/id/852600>

Organisation 2:

- Funder: Swiss Network for International Studies
- Grant title: The Impact of Menstrual Health Management on the Vaginal Microbiome: Linking Transdisciplinary Health Science and Policy to Improve Safety and Hygiene for the Benefit of Women's Health in Isala sisterhood countries Cameroon, Peru, Switzerland and Belgium
- Award period: 2024-2025
- Value: 246 034.11 BGP
- Weblink: <https://snis.ch/projects/the-impact-of-menstrual-health-management-on-the-vaginal-microbiome-linking-transdisciplinary-health-science-and-policy-to-improve-safety-and-hygiene-for-the-benefit-of-womens-health/>

## 6.2. Academic/Professional Publications

- Lebeer, S.\*, Ahannach, S.\*, Wittouck, S.\*, Gehrmann, T.\*, Eilers, T., Oerlemans, E., Condori, S., Dillen, J., Spacova, I., Vander Donck, L., Masquiller, C., Bron, P., Van Beeck, W., De Backer, C., Donders, G., Verhoeven, V., A citizen-science-enabled catalogue of the vaginal microbiome and associated factors, *Nature Microbiology* (2023)

Link: <https://www.nature.com/articles/s41564-023-01500-0>

- Eilers, T., Dillen, J., Ahannach, S., Vander Donck, L., Van De Vliet, N., Wittouck, S., Lebeer, S. *Lactobacillus isalae* sp. nov., isolated from the female reproductive tract. *Int. J. Syst. Evol. Microbiol.* 73:006038 (2023)  
Link: <https://www.microbiologyresearch.org/content/journal/iisem/10.1099/iisem.0.006038>

### 6.3. Other publications

- Ahannach, S.\* , Delanghe, L.\* , Spacova, I., Wittouck, S., Van Beeck, W., De Boeck, I., Lebeer, S., Microbial enrichment and storage for metagenomics of vaginal, skin, and saliva samples. iScience 24, 103306 (2021)  
Link: [https://www.cell.com/iscience/fulltext/S2589-0042\(21\)01275-X?](https://www.cell.com/iscience/fulltext/S2589-0042(21)01275-X?)

returnURL=https%3A%2F%2Flinkinghub.elsevier.com%2Fretrieve%2Fpii%2FS258900422101275X%3Fshowall%

- Cauwenberghs, E., Oerlemans, E., Wittouck, S., Allonsius, CN., Gehrmann, T., Ahannach, S., De Boeck, I., Spacova, I., Bron, PA., Donders, G., Verhoeven, V., Lebeer, S. Citizen-science map of the salivary microbiome in healthy women. *mBio*. 00300-23 (2023)

Link: <https://journals.asm.org/doi/full/10.1128/mbio.00300-23>

#### 6.4. Other forms of communication, including conferences

- Microbiome Medics podcast

Title episode: The Vaginal Microbiome with Professor Sarah Lebeer: a Triumph of Citizen Science

Link: <https://open.spotify.com/episode/3p0bX9LFg0Dv5xGidkrgBu?si=LbluzJJSQwWvTz6-Z7B4Kg&nd=1&dlsi=04d2100fc9b34162>

- We have a dedicated webpage with Isala mentions in the press (printed, online, podcasts, radio, etc.) : <https://isala.be/pers/>

## 6.5 Other Evidence

## -Awards

-European Union Grand Prize for Citizen Science: <https://ars.electronica.art/aeblog/en/2023/07/12/lets-swab/>

-EOS Science Magazine: <https://www.eoswetenschap.eu/tag/isala>

-Royal Academy for Science and Art: <https://kvab.be/nl/nieuws/onderscheidingen-wetenschapscommunicatie-2021>

-The Isala website holds a blog collection by team members, sisterhood projects and collaborators:

<https://isala.be/en/blog/>

- Examples of community outreach

-Nerdland Festival (2023)

- Vulva Weekend at GUM museum (2023)

-International Day of Microorganisms at Science museum (2022-2023)

- Day of Science (2018-2022)

-Sisterhood: <https://isala.be/en/the-isala-sisterhood-lets-write-history-together/>

-Leke project (Cameroon): <https://isala.be/en/the-leke-project-a-journey-to-the-isala-sister-project-in-cameroon/>

-Dora project (Nigeria): <https://isala.be/en/meet-dora-our-sister-project-for-vaginal-health-in-nigeria/>

-Laura project (Peru): <https://isala.be/en/starting-the-sisterhood-on-vaginal-health-now-in-peru/>

-Fatima project (Morocco): <https://isala.be/en/meet-fatima-our-brand-new-sister-project-to-study-vaginal-health-and-hpv-in-morocco/>

-Florence project (Uganda): <https://isala.be/en/isala-and-her-sisters-two-british-midwives-in-peru/>

-VLIR-UOS community talks: Improving women's health in Peru

<https://www.youtube.com/watch?v=0c20jL921G0&list=PLHzoIO0e6tUqImaZaSSbf0yNehi904-Tt&index=12>

How did you find out about the award?

Recommendation from a friend or colleague

By submitting this application you agree that your personal data will be used as part of, and to communicate with you about the Nature Awards programmes.

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