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## ABSTRACT

**Introduction** Health reporting is one of the foundations on which public health interventions and policies as well as prevention measures are developed. However, it faces the challenge of adequately reflecting social and sex/gender-related heterogeneity. The German Federal Ministry of Education and Research-funded joint project, AdvanceGender, aims to develop guidelines for sex/gender-sensitive and intersectional approach to population-based studies and health reporting. In its subproject, AdvanceHealthReport, four focus groups will be conducted to provide essential information on possible ways of participation of civil society stakeholders and on communication of health information for the further development of the guidelines (research period: from January 2019 to March 2020).

**Methods and analysis** The civil society stakeholders provide valuable information which health topics are relevant in regard to specific populations and how health information should be communicated in a non-stigmatising way. The groups will also discuss how civil society stakeholders should participate in health reporting. The starting point for intersections will be sex/gender. The intersection of sex/gender and migration and sex/gender and sexual orientation is particularly taken into account. The focus groups will be recorded, transcribed, anonymised and then analysed according to the qualitative content analysis.

**Results** The results will show the pathways as well as benefits and possible limitations of civil society stakeholder involvement in national health reporting and will contribute in developing guidelines for sex/gender-sensitive and intersectional health reporting.

**Ethics and Dissemination** The results of the focus groups will be published in scientific journals and presented at various national and international conferences. Furthermore, the findings will be incorporated into guidelines for research and health reporting. The study was approved by the Ethics Commission of Brandenburg Medical School Theodor Fontane (AZ: E-01–20180529).

## Strengths and limitations of this study

- The focus groups provide health reporting with information on which health issues are relevant from a civil society perspective and how health information should be interpreted and communicated.
- Intersectionality represents an innovative perspective to expand the approach of sex/gender-sensitive health reporting regarding greater social heterogeneity.
- Sampling is selective; therefore, the analysis of results must reflect which perspectives and stakeholders are (not) represented.
- The format of the focus group as a form of possible participation of civil society stakeholders is tested.
- The conditions and possibilities of different forms of future participation are not set by health-reporting officials, but formulated and discussed by the civil society stakeholders themselves within the focus group.

## INTRODUCTION

Health reporting is one of the foundations on which public health interventions and policies as well as prevention measures are developed. In Germany, the Robert Koch Institute (RKI) is responsible for federal health reporting.<sup>1</sup> On behalf of governmental bodies, the health reports compile and assess the existing knowledge on the population's health by relying on a broad variety of data sources and providing information for a wide range of target groups. Because of its pluralistic image, health reporting in Germany addresses a broad audience. Health reports provide reliable information for discourses between governmental and non-governmental (NGO) stakeholders on problem definitions and relevant fields of



action; thus, they enable the formation of political opinions and support political participation.<sup>2</sup>

Intensive discussions about the integration of sex/gender into health research and avoidance of gender biases<sup>3</sup> have led to data stratification in health reporting according to a dichotomous category: male/female. With this distinction it is not clear whether sex or gender is addressed. Furthermore, this stratification by itself does not ensure sex/gender sensitivity. Sex/gender groups are currently presented rather homogeneously and heterogeneity within sex/gender-groups and the issues of sex and gender have received little attention to date.<sup>4 5</sup> Health reporting faces the challenge of adequately reflecting social, sex and gender-related heterogeneity, which entails the need to include theoretical approaches explaining sex and gender differences.<sup>6</sup> Not only should sex-linked biological characteristics and their interrelations with gender be included in health reporting, but also gender itself. Health reporting should compare health differences by analysing institutional, structural aspects and social constructions of femininity and masculinity that influence cultural conventions, social roles and identities.<sup>7-9</sup>

To better represent societal diversity, the joint project AdvanceGender (funded by the German Federal Ministry of Education and Research) aims to promote the development of a sex/gender-sensitive and intersectional approach to population-based studies and health reporting. The three subprojects are devoted to study participation, data analysis and health reporting to develop recommendations for sex/gender-sensitive and intersectional research and health reports. Given the pluralistic image of the federal health reporting, one work package from subproject three (AdvanceHealthReport) raises the question of the information needs of different user groups. The setting of contents and the formulation of needs for action are still mostly carried out from a scientific perspective and follow the principle of top-down reporting.<sup>10</sup> The potential audiences of health reports, such as civil society stakeholders, can simultaneously provide valuable insights on health issues under certain living conditions that are mainly based on non-scientific expertise. These perspectives are assumed to possibly receive more attention in health reporting to create a need-based information basis.<sup>2 10 11</sup>

Four focus groups will be conducted to provide essential information on possible ways of participation of civil society stakeholders and on communication of health information for the further development of the guidelines. Additionally, the focus group format is tested as a participation tool to get practical insight in its benefits and limitations not only for us but also for the participants. Thus, the focus group approach tests to what extent the politically and scientifically driven process of producing governmental reports on the health of the population can be subject to a participatory opening towards civil society and how the content, language and structure of health reports would consequently change.

This approach is fruitful, as the participants can not only discuss theoretically different forms of participation, but also experience within the focus group how participation can be realised.

Recognised guidelines on reporting qualitative research were considered while writing the present study protocol.<sup>12 13</sup> In particular, issues concerning the background and rationale of the study, the composition and the role of the research group, the methodological approach to data collection and analysis and ethics and data protection were considered.

## METHODS AND ANALYSIS

### Qualitative approach and research paradigm

The term 'gender' was introduced into public health research to overcome a simplistic view of sex differences based on biology. In this sense, the term 'gender-sensitive' aims at understanding the specific living conditions and needs of people that are influenced by the institutional, structural and social constructions of femininity and masculinity.<sup>3 14 15</sup> The AdvanceHealthReport subproject broadens a sex/gender-sensitive approach into an intersectional perspective.

A central idea of the intersectionality perspective is that through intersecting categories of societal difference (eg, gender identity, migration, age), specific living conditions and health emerge. This approach is open to a plural and non-binary understanding of sex and gender<sup>16</sup> encompassing the societal and biological diversity between and within sex/gender groups. Within the intersectional perspective, no category is set as the analytical master category (understood as the main category, which is always relevant and the main influencing factor).<sup>17</sup> Instead, we understand sex/gender as a starting point for the intersectional analysis. Therefore, the analysis is open to the question whether sex/gender is important at all and how it interacts with other societal categories of difference.<sup>18 19</sup> The societal diversity is made visible by analysing sex and gender as intersecting with other categories of social difference. In this study the intersection of sex/gender and migration and of sex/gender and sexual orientation is particularly taken into account. These categories do not add up, but interact under the present institutional and structural conditions and form privileged and disadvantaged living conditions that eventually lead to health outcomes.<sup>17 20 21</sup>

Furthermore, gender is understood not as an individual characteristic, but as a relational societal category. The intersectional perspective explains gender-related health inequalities by considering the cultural, institutional and structural contexts of the society.<sup>14 22</sup> Thus, intersectionality analyses health related inequalities as consequences of multiple interactions that are framed by cultural patterns, such as constructions of femininity and masculinity, and institutional and structural aspects, such as how the healthcare sector is organised.<sup>3 16</sup>

Our approach aims to make social differentiations visible and calls for greater participation of the societal groups represented in the research process. To better represent different needs, it is suggested that societal groups affected by health inequalities should play a more active role in the research process itself.<sup>17</sup> This should not only increase their visibility, but also strengthen the validity of explanations of health data. From a methodological point of view, this requires a discursive opening of the processes of knowledge generation and transfer to non-scientific perspectives. Drawing from the model of different stages of participation our study is limited to a preliminary stage of participation (stage 4), in which we listen to civil society and their conditions and ideas for possible future participation.<sup>23</sup>

The intersectionality research approach of the present study is reflected in the research questions, sampling and data analysis. The focus groups are suitable for collecting information on which health aspects are deemed relevant by civil society actors. Expert knowledge is collected from many individual living contexts (in-depth knowledge) and structural and institutional contexts (system knowledge). The focus group design was given preference over other methods (eg, expert interviews) because it opens up the possibility of bringing together various perspectives in the discussion. Therefore, it is possible to bring together and discuss central arguments as well as to give room to neglected theses. Furthermore, in an explorative process of data collection, this approach tests the opportunities and limitations of the participation of societal groups in the official health-reporting process.

### Research team and reflexivity

All researchers are members of the Federal Health Reporting unit at the RKI. Therefore, the study will not be carried out by neutral, external scientists, but is a self-reflexive research study developed by health-reporting experts. The research questions emerged from challenges for sex/gender-sensitive health reporting identified by the researchers in the course of designing and producing sex/gender-related health reports.<sup>5 18 24</sup> Therefore, the project partially follows a pragmatic approach. The further development of health reporting as an outcome of the study is not only guided by what is desirable in terms of sex/gender research and theory, but the study also considers what seems feasible, particularly with regard to the conclusions that are drawn, within current health-reporting practices and with the given resources in Germany.

The focus groups are being conducted by KP, AR and SMS. KP and AR are sociologists (PhD) by training and work as project coordinator/researcher (KP) and project manager (AR). SMS is a midwife by training and a public health student (BA candidate) who works as a project assistant. KP and AR work at the level of senior researchers and have long-standing experience in conducting qualitative research, especially theme-centred interviews (KP), expert interviews (AR) and (focus) group discussions

Perspective on:	Sex/Gender	General Perspective on FG topic	Migration	Sexual Orientation	Age	(Dis)Ability	Socio-economic Status	Health Reporting Expertise
<b>Focus Group 1: Women's Health</b>								
P1	X	X						
P2	X		X					
P3	X			X				
P4	X				X			
P5	X					X		
P6	X						X	
P7	X							X
<b>Focus Group 2: Men's Health</b>								
P1	X	X						
P2	X		X					
P3	X			X				
P4	X				X			
P5	X					X		
P6	X						X	
P7	X							X
<b>Focus Group 3: Sex, Gender and Sexual Diversity</b>								
P1	X	X		X				
P2	X	X		X				
P3	X		X	X				
P4	X			X	X			
P5	X			X		X		
P6	X			X			X	
P7	X			X				X
<b>Focus Group 4: Sex/Gender and Migration</b>								
P1	X	X	X					
P2	X	X	X					
P3	X		X	X				
P4	X		X		X			
P5	X		X			X		
P6	X		X				X	
P7	X		X					X

**Figure 1** Sampling plan for the four focus groups.

(KP, AR). SMS is new to the field and this is her first qualitative research study. KP and SMS are experienced in the moderation of non-scientific antidiscrimination training in schools focusing on sex/gender and sexual diversity (SMS) as well as on sexism and racism (KP). The researchers have no migration background and are between 30 and 47 years old. Regarding an intersectional research approach, the perspectives represented in the focus groups are more diverse than in the research team. Within the research process, the team reflects on these social differences inscribed in societal power relations and communicates them transparently to the participants.

### Sampling strategy

The sampling strategy follows an intersectional approach to highlight the heterogeneity within sex/gender groups. Four focus groups are being conducted with each focusing on sex/gender and health (figure 1). One group focuses on women's health and another on men's health, as each respective group represents a major gender identity, as well as a sex-linked, biologically defined group. As we think of sex and gender as being non-binary, we conduct the third focus group on sex and gender diversity, considering cis-gender, trans\* (The asterisk comes from search engines where, eg, trans\* searches for all words starting with trans. It is intended to cover all self-understandings of this area that begin with 'trans-'. It serves as a placeholder for various gender identities (eg, trans woman, non-binary, agender) and sex-linked characteristics (eg, various physiological variations in transitioning to another gender), queer and inter\* in intersection with sexual orientations, such as lesbian, gay, bisexual and heterosexual. In this group, we broaden the perspective regarding sexual orientations because the societally dominant heteronormative order has a major impact on



the health of lesbian, gay, bisexual, trans\*, inter\* and queer populations. The fourth group centres on the intersection of sex/gender and migration with respect to health. In 2017, 23.6% of the German population had a migration background (ie, they were born either themselves or at least one parent without German citizenship) showing a marked within-group heterogeneity.<sup>25</sup> This is also reflected in the differences in certain aspects of the health situation of some migrant groups from that of the overall population. Specific barriers in the healthcare system might be relevant, such as discrimination and language barriers. Therefore, we decided to conduct a focus group specifically considering this intersection.

Sex/gender and health are the main thematic focus within all groups. Sex/gender is the starting point, but will be analysed as intersecting with other social difference categories. We consider certain social categories in each focus group: for example, migration, sexual orientation, age, (dis)ability and socioeconomic status. This enables thematic comparisons regarding specific intersections across different focus groups. In this way, different and sometimes contrary views can be captured in one thematic area and—within a certain scope—the societal heterogeneity will be reflected. We also invite one to two persons with a more general perspective on the specific topic of each focus group to support the contextualisation and connecting of the different views.

In accordance with the intersectional approach, we understand the categories migration, sexual orientation, age, (dis)ability and socioeconomic status as social power relations that go hand in hand with privileges and disadvantages. For this reason, we take into account different positions within the power relations. In the women's health group, for example, we have representatives of young, middle aged and old population groups. The same is done with the other categories. This approach allows us to include representatives of more privileged but also of more societally marginalised groups. The individual participants will not represent an entire social group but the organisation they belong to. Within these organisations different perspectives of a social group are included and some might not. This aspect will be taken into account within the data collection and analysis.

Each focus group consists of seven participants each. We invite representatives from counselling centres, healthcare providers, public health services, professional associations and NGOs. Each focus group includes one representative from health reporting at a national, federal or community level. Integrating the health-reporting perspective enables a dialogue between pragmatic and activist perspectives.

Furthermore, every focus group should be composed of a diverse sample. The selection criteria included a distribution of participants from urban and rural areas because of the different healthcare structures depending on the region in Germany. A second selection criterion is the size of the represented organisations, which reflects not only on the power relations within the field of NGOs,

but also in the German society. Certain interest groups are better organised and are better integrated into political discourse than others. By including different types and sizes of organisations, we expect to obtain diverse perspectives on the intersections of societal categories of difference. Every participant in this field should have an activist or working expertise as well as a personal identification (eg, having a migrant background or identifying as queer) in the discussed field that they represent. This criterion is important to facilitate a discourse where societal groups are represented by their own members. This applies also to sex/gender: In the groups on women's and men's health and on sex/gender and migration, participants are not only, but predominantly persons who identify with their assigned sex at birth (cis-gender). In the focus group on women's health, women (cis-gender) will be the main participants, but there will also be some trans\* persons. The same applies to the focus group on men's health. In the focus group on sex/gender and migration there are in equal proportions mainly cis-gender men and women, but trans\* perspectives are also included. In the focus group on sex/gender and sexual diversity cis-gender, trans\* and inter\* perspectives should be represented equally.

To identify potential participants, stakeholder mapping is carried out based on online research. After identifying the relevant civil-society institutions, we contact them via an email that briefs the participants on the objectives of the study. Afterwards, we call the potential participants to discuss open questions and explain the purpose of the study and the participants' role more deeply. Because of the power relations of the societal context and between civil society and a governmental institution, such as RKI, it is important to personally contact the participants to build a relationship based on trust. For transparency, therefore, we present our research questions, goals, methods and data protection regulations to the participants from the very beginning.

The participants sign a declaration of consent stating that they voluntarily participate in the study. In addition, they sign that they have taken note of their data protection rights listed in the consent form, that the audio recording of the focus group is transcribed and analysed for the purpose of the study, and that the study results are stored and published in an anonymised form. For the implementation of the focus groups, information is not obtained from patients or private individuals, but from professionals or volunteer representatives of NGOs. Convenience sampling is performed by the RKI exclusively via publicly accessible information, for example, addresses that are available from websites. The NGOs send representatives to the focus groups who represent the perspective of their clientele and organisation in the focus group discussions. The participants' institutional addresses, names and audio recordings are stored separately from the other data and deleted within 3 months after the focus group. No other personal or private data are collected. The transcripts of the audio records of the

focus group discussions will be stored permanently in an access-protected project folder at the RKI. To protect our participants' anonymity and regarding their declared data protection rights, the data will not be made available for secondary analysis. The data protection commissioner of the RKI has examined the study and declared that it is safe to conduct under data protection law.

### PATIENT AND PUBLIC INVOLVEMENT

In this study we do not collect data from patients. Therefore, patients were not involved in the development of the research question, outcome measures, design, recruitment and conduct of the study.

### DATA COLLECTION

All focus groups are held in the RKI as 1-day events (research period: from January 2019 to March 2020) lasting 4 hours. The participants are reimbursed for their travel expenses and receive an allowance. Apart from the researchers and participants, there are no third parties attending the discussions. The focus groups are digitally recorded on a mobile dictation machine (WS 650S; Olympus, Hamburg, Germany).

During the recruitment process, the participants receive an information sheet on the study and on the data protection regulations concerning data collection, procession, analysis and publication. Before the focus group starts, the participants have time to ask about data protection and sign the consent forms. Additionally, at the beginning of each focus group the participants agree not to discuss outside of the focus group who else attended, which organisations were represented or any specifics of what was discussed.

The focus groups are moderated group discussions about a topic defined beforehand.<sup>26 27</sup> The discussions focus on the representation of sex/gender and societal diversity in health reporting. They start with brief presentations about health reporting in general (eg, definition, function, current practice, challenges regarding sex/gender-sensitivity and intersectionality) by the project manager (AR), about the project AdvanceGender (eg, aims, concept, work packages), and the structure and goals of the focus group itself by the moderator (KP). The researchers and their role in the project are introduced to the participants in detail. After that, the participants will briefly present themselves and give some information about their working areas. This introductory session will take 30 min.

We present sex/gender in an intersectional perspective in health reporting as our main interest. We do not ask questions about specific intersections, but since our participants are very familiar with the social group they represent, they answer our fairly comprehensive questions with regard to the health of specific population groups characterised by specific intersections.

The focus groups comprise three thematic segments lasting 1 hour per segment, which are each briefly introduced by a thematic impulse. The first question, 'What health issues should we report and why?' is introduced by a current example of the structure of a health report. The participants then have 5 min to write key words onto moderation cards, which they subsequently explain to the group. The cards are then pinned by the research assistant (SMS) to a pin board under the visualised question and clustered thematically along the currently most-important thematic areas of reporting: for example, 'physical health', 'mental health', 'health behaviour' and 'healthcare'. In addition, the further category, 'other', should provide an opportunity to question the given categories, add further aspects and show the interrelations and mechanisms of health in/equalities. After each participant has presented their keyword cards, all participants discuss the resulting chart together and can make additional comments.

The second question, 'How should we report the health needs?' will be introduced by an extraction from a health report relevant to the thematic focus of the group (eg, migrants' health). The discussion evolves around the question how existing findings can be interpreted in a resource-oriented manner, which avoids the repetition of misleading stereotypes, stigmatisation and discriminatory language. The discussion is moderated by KP and SMS writes down the main keywords and aspects of the discussion and pins it on the pin board under the discussed question.

The third question, 'How should civil society stakeholders participate in health reporting?' is introduced by a short presentation about the process of health reporting that is visualised using a flipchart. This should give the participants ideas about the participation of civil society stakeholders during the different phases of health reporting. KP moderates the discussion and SMS writes keywords and put them on the pin board.

After the three thematically focused discussions, an open space of 25 min provides participants with the opportunity to address aspects that they consider to be important. The final round will last 5 min, in which the researchers thank the participants, who are offered the possibility of a final comment.

### Data processing and analysis

The audio records and transcripts are stored in a strictly access-protected project folder only accessible by KP. The audio data are transcribed by a contracted person who works at a password-protected guest workstation without an Internet connection in RKI. The contractor has read-only access to the audio files and performs the transcription using the SpeechExec Enterprise Dictation and Transcription software (V.4.1; Philips, Amsterdam, The Netherlands). Once an audio file has been transcribed, the anonymous transcript is stored in the access-protected project folder, which is only accessible by KP. The audio files and transcripts are deleted from the

transcription staff's personalised guest workstation. The researchers continue to work with the anonymous transcripts. Computer-assisted coding is performed using the MAXQDA V.12 software program (VERBI, Berlin, Germany), which allows for an efficient reliability check and documentation of the development of the code scheme.

Qualitative content analysis is used to compile and systematise the main outcomes of the focus groups.<sup>28</sup> The categories are at the centre of the qualitative content analysis because they guide the interpretation of the text. We combine inductive category development and deductive category application. The deductive category application brings theoretical informed and prior formulated categories together with the text analysis. The analyses are guided by our three questions mentioned earlier.

The inductive categories are developed successively. In the first step, the category definition and the level of abstraction are defined. Following this criterion, categories and subcategories are formulated while working through the transcripts. The categorical system is developed further with every transcript. The research team revises the categories after completing 30% of a transcript and after completing the full transcript for reliability checks. After all, four focus groups are worked through, the categories will be discussed by the full team, revised and reduced to the main categories. After that, a final work through the text will take place.

### Dissemination

The results of the focus group discussions will be presented at various national and international conferences. After the first focus groups are conducted the preliminary results will be presented to a scientific community (scientific conferences), experts of health reporting (eg, at an annual federal workshop) and civil society (eg, annual conference on poverty and health). The results will also be published in scientific journals. Furthermore, the findings will form an important input for a subsequent Delphi study in which researchers and health reporters develop guidelines for sex/gender-sensitive and intersectional health-reporting practices.

**Collaborators** On behalf of the study group AdvanceGender (University of Bremen, Institute of Public Health and Nursing Research, Department of Social Epidemiology (Gabriele Bolte, Emily Mena), Robert Koch Institute (Alexander Rommel, Kathleen Pöge, Anke-Christine Saß, Sarah Strasser), Brandenburg Medical School Theodor Fontane, Institute of Social Medicine and Epidemiology (Christine Holmberg, Sibille Merz, Philipp Jaehn)).

**Contributors** KP, AR, and SMS designed the study, organised the focus groups and collected the data. KP and AR drafted and wrote the manuscript. SMS and A-CS supported the drafting of the manuscript. SMS and A-CS reviewed and commented on the preliminary version of the manuscript. KP and AR revised the manuscript. All authors have read and approved of the final manuscript.

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**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** The study was approved by the Ethics Commission of Brandenburg Medical School Theodor Fontane (AZ: E-01-20180529).

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