Representing Sex and Gender Information in Biomedical Research

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Abstract. In medicine and biomedical research, sex- and gender-related aspects are ubiquitous. If not considered adequately, a lower quality of research data can be expected together with a lower generalizability of study results with real-world settings. From a translational perspective, a lack of sex- and gender-sensitivity in acquired data can have negative implications for diagnosis, treatment (outcome and side effects), and risk prediction. To establish improved recognition and reward settings we set out to develop a pilot of systemic sex and gender awareness in a German medical faculty, with actions such as implementing equality in routine clinical practice and research, as well as in scientific practice (incl. science education). We believe that the change of culture will have a positive effect on research outcomes, lead to a rethinking in the scientific domain, foster sex- and gender-related clinical studies, and influence the design of good scientific practices.

Keywords. sex and gender, data life cycle, semantic enrichment

1. Introduction

In medicine, sex and gender-related aspects are ubiquitous and can be found in epidemiology, pathophysiology, clinical manifestations, psychological effects, disease progression, and response to treatment [1]. In this context, sex refers to biological constructs, whereas gender refers to social constructs. Sex and gender are genetic, biological, and environmental modifiers of acute and chronic diseases. Inadequate or insufficient consideration of sex and gender in medical research leads to reduced data quality and non-reproducibility of scientific outcomes [2]. From a translational

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perspective, a lack of sex- and gender-sensitivity in the data can have serious implications for diagnosis, treatment (outcome and side effects), and risk prediction [1].

2. InkE – Excellence through Inclusiveness in Medicine

InkE is a project at the University Medicine Greifswald, Germany, in close collaboration with Greifswald University's Faculty of Arts and Humanities, Graduate Academy and central gender equality office. The project team develops concepts, actions, and tools that all target the gender gaps in medical research and education.

  One project goal is to change the system of academic recognition and reward. The current one-sided emphasis on traditional, quantifiable output indicators (e.g., number of publications, h-index and journal impact factor) is one of the causes of (implicit) gender bias. In order to achieve excellence, we aim for a renewed system of recognition and rewards that: (1) enables the diversification and vitalisation of career paths; (2) acknowledges the independence and individual qualities and ambitions of academics as well as recognising team performances; (3) emphasises quality of work over quantitative results; (4) encourages all aspects of open science; and (5) encourages high-quality academic leadership (see also https://recognitionrewards.nl).

  A second goal is to encode sex and gender information in clinical and epidemiological studies. Good scientific practices for clinical and epidemiological studies exist and efforts have been made to harmonize and publish interoperable data models and metadata, e.g. [3]. However, a first analysis of data dictionaries for a sample of German studies revealed that only little information on participants' gender is recorded as of now. To complicate matters, in German, the term 'Geschlecht' simultaneously refers to both sex and gender – leading to unawareness or even lack of distinction between the two concepts. To overcome this situation quickly, we propose a fine-grained encoding of such information using domain ontologies [4]. Gender variables should be semantically enriched throughout the data life cycle, during data retrieval and exploration. Such provenance information will allow for gender-studies involving changes of gender in patients and consequences thereof in the context of medical care.

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