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# Science with and for Society: Emergency (PHE) threat Public health emergencies: response and preparedness

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# Science with and for Society (SwafS): The case for Epidemics & Pandemics

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There are times when science seems to be losing its connection to society and its needs, and its objectives are not fully understood, even if they are well intended. The lack of a common language on one hand and the rapid progress in many areas of research on another has increased the public's concern. It is also contributing to the ambivalence surrounding the role that science and technology are playing in everyday life. However, science and scientists cannot and should not work in isolation, and advances in science and technology are not an objective in their own right.

The European Commission has published already on 4 December 2001 a Communication setting out the Science and Society Action Plan (ec.europa.eu/research/swafs/pdf/pub\_public\_engagement/ss\_en.pdf),

which was based on a staff working paper of November 2000 titled 'Science, Society and the Citizen in Europe', followed by a resolution by the research ministers to bring science and society closer working both at national and EU level.

Science with and for Society or SwafS is the two-way communication of Science with Society.

As a consequence of the above, the European Commission has committed resources every year since 2002 into making science more attractive (notably to young people), raising the appetite of society for innovation, and opening up further research and innovation activities. A number of EU projects have been developed and realized in the Framework Programme (FP) 6 with budget of 80 million Euros, expanding to 330 Million € in FP 7 and continuing into the Science with and for Society and Responsible Research and Innovation theme in Horizon 2020 (2014-2020), which is a cross-cutting issue with a budget of 462,2 Million Euros.

SwafS in particular as regards epidemics and pandemics is an extremely interesting although less developed area of Science in Society (SiS). In times of public health (PH) crises such as in the event of outbreaks, epidemics or pandemics a number of SwafS issues may prove critical for the response and the control of an outbreak.





Issues like the effect of a pathogen on a specific population or gender (e.g. pregnant women with A(H1N1)pdm09 or currently with Zika virus), recommendations on immunization esp. in emergency situations such as during an influenza pandemic, or even the need to enforce quarantine in some cases, are some only of the scientific issues that need to be well understood by the society in order to ensure the compliance of the public and the successful control of an outbreak.

ASSET (Action plan in Science in Society in Epidemics and Total pandemics) is a 48 month Mobilisation and Mutual Learning Action Plan (MMLAP), which aims to:

1. forge a partnership with complementary perspectives, knowledge and experiences to address effectively scientific and societal challenges raised by pandemics and associated crisis management;

- 2. explore and map SiS-related issues in global pandemics;
- 3. define and test a participatory and inclusive strategy to succeed;
- 4. identify necessary resources to make sustainable the action after the project completion.

ASSET combines public health, vaccine and epidemiological research, social and political sciences, law and ethics, gender studies, science communication and media, in order to develop an integrated, transdisciplinary, strategy, which will take place at different stages of the research cycle, combining local, regional and national levels.

We are happy to introduce the ASSET scientific paper series with this first issue. The scientific paper series aims to present and discuss various scientific issues in relation to epidemics and pandemics in the form of an open access scientific quarterly newsletter, in collaboration with the experts in the ASSET consortium as well as invited authors.

We hope you enjoy all our communications!

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- 1. DG Research and Innovation, SWAF (<u>http://ec.europa.eu/research/swafs/index.cfm?pg=home</u>)
- 2. ASSET project (<u>http://www.asset-scienceinsociety.eu/</u>)





# Gender Issues in Pandemics and Epidemics

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#### ABSTRACT

**Introduction:** This study looks at gender issues in relation to the use of vaccinations in pandemics and epidemics.

**Methodology:** A semantic analysis on ethical issues was conducted of eleven national influenza pandemic plans (10 from European Union (EU) member states (MS) and one from Switzerland), including EU and WHO documents.

**Results:** The main gaps identified include lack of awareness for specific population groups on the importance of vaccinations.

**Discussion:** When creating awareness of the importance of vaccinations a more gendered approach is required.

#### **1.** INTRODUCTION

90% of all deaths from influenza occur in adults aged over 65 years, or among welldefined risk groups such as children under the age of 5, or those with underlying medical conditions [1]. Vaccination is widely recognised as the most effective way to prevent influenza infection [2]. Immediate access to an influenza vaccine is regarded as a major component of pandemic preparedness planning [3].

Differences based on sex and gender are important in understanding and improving outcomes and uptake rates for vaccination. A gender-specific focus can be described as "research (that) comes from an approach that is considerate of the multifaceted nature of gender" [4 p. 199]. Gender refers to socially constructed roles, behaviours, activities, and attributes that a given society considers appropriate for men and women. Sex refers to the biological and physiological characteristics that define men and women, boys and girls. Studies have found that differences between gender became smaller with age and statistically insignificant; while other studies found no difference by gender [1]. Bish et al found that amongst both the general population and health professionals, men were more likely to intend to be vaccinated and to be vaccinated than women [5].

These examples of research clearly show gender is not sufficiently or correctly analysed as a variable. This study aims to look at gender differences and the use of vaccinations in pandemics and epidemics. Exploring a life course approach to the uptake of vaccination programmes requires adopting a societal perspective.





#### 2. METHODOLOGY

The study is divided into two parts, a literature review and semi-structured interviews with eight key stakeholders.

#### 2.1 LITERATURE REVIEW

For the literature review, searches were conducted to identify papers in peer-reviewed journals on the topic of gender, epidemics and pandemics. Searches of databases included PubMed. Web of Science. Embase and terms "gender". CINHAL using search "pandemic", "influenza", "vaccine", and "epidemic" between August 5 and 10, 2014. No date restrictions were applied to the searches. In addition, the databases of Eurostat, Centre for Disease Control (CDC), European Centre for Disease Prevention (ECDC), World Health Organisation (WHO), International Longevity Centre (ILC), and the European Medicines Agency (EMA) were searched as well as Google to find any additional literature.

#### 2.2 STAKEHOLDER INTERVIEWS

For the stakeholder interviews, qualitative semi-structured interviews were conducted (See Appendix A). A list of suitable stakeholders was compiled by the researchers, based on the reach of the organisations and the stakeholder's involvement. The researchers transcribed all interviews verbatim, and analysed the transcripts using Framework Analysis, which was deemed to be the most appropriate approach [6].

#### 3. RESULTS

#### **3.1 LITERATURE REVIEW**

#### Sex differences in influenza and vaccination

Biologically, females and males differ in their immunological responses to seasonal influenza virus vaccines. The antibody response of a female to half a dose of influenza vaccine is equivalent to the antibody response of a male to the full dose [7].

Women also report a worse reaction to vaccinations than men do [8]. These adverse reactions may be caused by the dose being too high. More research is needed into this area; female reactions to vaccinations should be incorporated into clinical trials and sex and gender should be considered when evaluating the efficacy of antiviral treatments [9].

#### Pregnancy

Women who are pregnant are more likely to have severe disease and hospitalisation with either seasonal or pandemic influenza. During pandemics, the mortality rate for pregnant women is higher than non-pregnant women, however this is not the case with seasonal influenza [9].

The WHO recommends all pregnant women to receive vaccinations during the influenza season, and that they should be given highest priority among all the at-risk groups [10]. Yet, despite such recommendations, vaccine coverage for pregnant women tends to lag behind the general population [8].

Evidence points to pregnant women not knowing of the increased risks associated with pregnancy and influenza; also, many health care providers do not recommend pregnant women to take vaccine due to concerns over giving a vaccine to a pregnant woman [9]. Such





inconsistent advice from relevant health care providers is an obvious obstacle to uptake of vaccination for pregnant women [11].

#### Health care workers

Women represent more than 50% of the healthcare workforce in many countries; also, in most countries nurses, teachers and childcare workers are mainly female [9]. For example 80.2% of employees in the Irish health services are women, while women account for 92.1% of nurses [12]. Front-line workers face disproportionate risks of illness and death during a pandemic [13]. Studies have generally shown compliance rates from as low as 10% to 40-50% among health care workers, with no clear pattern to ascertain why this is [14]. There exists little consensus on how to target the low vaccination rates of health care workers, and more research is urgently needed.

#### Underlying medical conditions

People with already existing conditions, such as cardiovascular diseases. diabetes. and pulmonary/respiratory disease, are at greater risk from influenza [15]. Women are more likely to have diabetes in their lifetime than men, and studies in the US show that women, particularly those in lower socioeconomic groups, receive less adequate diabetes care than men from the same socioeconomic group [9]. Vaccinations along the life course trajectory should be considered a normal part of adult life and not just childhood, and that emphasis on vaccination should include those over 50 years of age [16]. Lowering the age limit for vaccination may be effective in increasing vaccine uptake [11]. A Spanish study found that among those under 65 years of age with chronic conditions, influenza vaccination figures are very low at approximately 30% [17]; changing the vaccination age limit to 50 and over may help increase this number.

## Hard to reach groups

Hard to reach groups may have adverse health outcomes, and the complex interplay of gender and social and economic marginalisation makes this a particular issue for women [18]. There are a number of minority groups in society which have adverse health outcomes and where women are particularly affected, for example the Roma community and Irish Travellers. Women in hard to reach groups are particularly marginalised.

It is recommended to create environments that improve access to health, and health-seeking behaviour for all. Engaging in strategies that increase educational attainment for women are important in redressing inequities that contribute to adverse health outcomes [18, p. 1038].

#### Older women

Persons over the age of 65 have a higher risk for severe influenza-related complications and have the highest risk of mortality from influenza. Vaccination of older persons have traditionally been the main focus of influenza vaccine policy and remains the most effective public health tool to protect against influenza [10]. Issues such as increased frailty, ill health, widowhood, and social isolation create barriers to the uptake of vaccinations by older women. More inclusive clinical research, as well as more research and data collection on older women's health in general, is needed [18].

#### Distrust of vaccinations

In Europe, nine out of every 10 children receive at least a basic set of vaccinations



during infancy [19]. However, there is a great difference between being under-vaccinated, which might be due to marginalisation or healthcare inequalities, and un-vaccinated. Despite a comparatively high level of vaccination, there exists scepticism and distrust of vaccinations in Europe - some lack of awareness or interest in vaccinations, while some people refuse it based on philosophical grounds [20].

Communication and transparency are both at the centre of strategies dealing with distrust and scepticism towards vaccination. The role of the media, both traditional media and more recent social media, is crucial for disseminating information about pandemics, epidemics and vaccination. Interestingly, females are more likely than males to trust print media, the Internet, and television as a source of health information [21]. This has repercussions in terms of how to approach and connect with women who are sceptical about vaccinations. One systematic review [22] found that messages that consider demographic, ethnic and social differences allow for more effective and targeted communications. Based on this, they argued that vaccination coverage and protective behaviours may both increase if such improved communication strategies were to be employed while dealing with various specific groups, such as gender.

#### **3.2 LITERATURE REVIEW**

A total of eight stakeholders agreed to participate in interviews discussing gender perspectives of influenza epidemics/pandemics and vaccination. The stakeholders interviewed were:

• The Pharmaceutical Group of the European Union (PGEU).

• International Longevity Centre UK (ILC-UK).

- The Strategic Advisory Group of Experts (SAGE) on Immunisation, WHO;
- European Centre for Disease Prevention and Control (ECDC).
- European COPD Coalition (ECC);
- Confederation of Meningitis Organisations (COMO).
- Irish Nurses and Midwives Organisation (INMO).
- European Federation of Nurses Associations (EFN).

Below is a summary of the stakeholder findings based on the issues identified throughout the interviews.

#### Gender

Only one stakeholder reported having a specific focus on gender issues. Many stakeholders were of the opinion that influenza does not discriminate by gender – this belief leaves out the unique challenges presented by gender as detailed in the literature review.

#### Pregnancy

There was a high awareness and proactive behaviour from all stakeholders on this issue.

#### Communication

All involved participants continuously stressed the importance of effective communication, making it the largest issue identified in our data – however, this was identified more as a general problem.

#### Hard to reach groups

Some stakeholders recognised this problem, and the solution suggested was one of tailored and increased communication.





### Health Care Workers

Very little awareness of the gendered situation of this group.

#### Older women

The near absence of identified strategies or targeted messages for older women by the stakeholders make this an area where much more emphasis is needed.

#### 4. DISCUSSION AND RECOMMENDATIONS

Evidence compiled in this report from both the literature and the stakeholder interviews clearly shows that there is a need for a more gendered approach to influenza pandemics/epidemics and vaccination. A lifecourse approach to influenza vaccination is important for all groups; however the specific needs of women and in particular for hard to reach groups, are crucial for protection against influenza pandemics and epidemics. Identifying the population at risk and their specific needs will require a comprehensive public health communications strategy in order to promote awareness of this issue.

Based on this, we suggest the following recommendations:

- Health literacy should be considered in the development of all vaccination promotion initiatives at all levels and settings.
- Develop clear communication strategies at the EU, national and regional level on influenza pandemics/epidemics and vaccination.
- Promote increased awareness among health professionals in relation to vaccination and the importance of consideration of a life course approach.

• Update, clarify and standardise influenza vaccination advice materials for pregnant women.

- National vaccination strategies should include specific guidancesis on the needs of older women and men.
- More research is needed into the gendered effect of influenza and vaccination on healthcare workers and carers.
- Further research is needed into the barriers to accessing information on vaccination from a gender perspective.
- Research that target women's attitudes to influenza and vaccinations is recommended.
- Support the inclusion of women in clinical trials.
- Support the standardisation of data collection methods in relation to sex and gender.

#### **APPENDIX A**

1. How would you describe your communication strategy and/or your information policy in relation to vaccination take-up, and influenza epidemics/pandemics, from a gender perspective?

2. Does your organisation have any awareness strategy in relation to gender differences in vaccination strategy, or have you ever had one?

3. What are your organisation's policies on pregnant and breastfeeding mothers in relation to vaccinations? What is your general advice to pregnant/breastfeeding mothers in terms of vaccinations during influenza epidemics and pandemics?





4. How would your organisation inform older women and their specific needs in relation to influenza vaccination uptake?

5. Health care workers tend to be predominantly female. What particular emphasis does your organisation have on the female health care work force in terms of influenza vaccinations?

6. How does your organisation interact with health care workers such as GPs to avail of their role as advisors to the wider community regarding vaccinations during influenza epidemics/pandemics?

7. How does your organisation interact with caregivers from a gender perspective, and how do you engage specifically with them and their vaccination uptake in an influenza epidemic/pandemic?

8. How does you reach marginalised group/vulnerable groups in society in relation to vaccination uptake and gender specifics?

9. To what extent are you approaching vaccinations through a life-course strategy?

10. What information and research gaps do you see in epidemics and pandemics in terms of gender issues?

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# From Modelling Epidemics to Modelling Human Behaviour Impact on Epidemics: Perspectives for Science in Society by Alberto d'Onofrio<sup>1</sup>

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#### **1.** INTRODUCTION

This short paper has two interlinked aims. The first is to introduce some key concept of the "Mathematical Epidemiology" to the Science in Society (SiS) community, without going into mathematical details. Describing mathematical science without using mathematics can seem strange or even peculiar, but this is a task that can be easily achieved due to the particularly and intuitive structure of simple the mathematical models adopted in this discipline. The second and most important aim in the context of this publication is to introduce the SiS community to the existence of a new field of investigation in the arena of epidemic modelling: the behavioural epidemiology of infectious diseases. This new discipline, which aims to improve our knowledge of the spread of epidemics and pandemics by taking into the account human behaviour, is of the outmost relevance, for those interested in SiS, and viceversa.

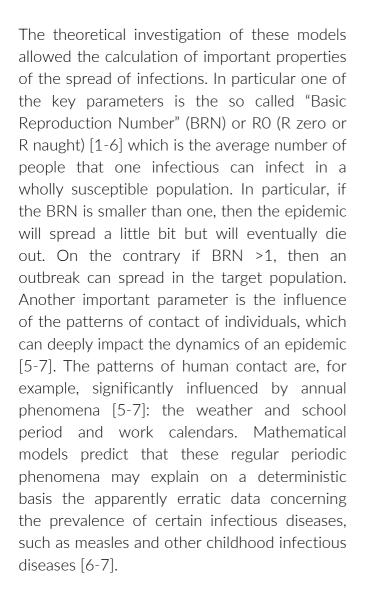
# 2. KEY CONCEPTS AND KEY RESULTS CONCERNING MATHEMATICAL MODELLING EPIDEMIC OUTBREAKS AND ENDEMICS

Simple modelling -and in particular a very simple (mathematically speaking) representation of the process of infection – can be amazingly

effective in describing what is a real complex phenomenon such as the spread of an infectious disease in a population[1-6]; the second, these models are effectively used by public health systems[4-6].

Indeed the mathematical models of the spread of infectious diseases are based on the following assumption[1-6]: the subjects are assumed as molecules moving in a chemical reactor and the disease corresponds to a chemical reaction upon the encounter of two of such molecules: one representing an infectious and one representing a healthy person susceptible to be infected. In chemistry if two reagent molecules enter in contact it does not automatically imply that the reaction actually takes place. The same holds when a healthy person enters in contact with an infectious one; the infection is probable but not certain. The result is that the susceptible can be infected (or not). Models can be more or less complex, and they can fine-tune this or that important detail, but this is the essence of such class of mathematical models. As a consequence, the tools used to analyse these models are more or less those used by chemical engineers and physicists when studying chemical reactions.





#### 3. MATHEMATICAL MODELS THAT CAN HELP PUBLIC HEALTH

Models can also be developed to test outbreak control measures, and in particular vaccination. For example, if one implements a mandatory vaccination campaign able to vaccinate a fraction F of the newborns, this is equivalent to a reduction of the RO to a smaller value: RO(1-F) [5-6]. This "effective BRN" can be used to determine the minimum fraction F of vaccinated children needed to eliminate the disease from the target population: Fmin=1-(1/ RO) [5]. This theoretical result can explain why it is very hard to eradicate infectious diseases such as measles: they have a very large BRN, which implies that the Public Health authorities have to make the effort to vaccinate a percentage of newborn that is very close to 100% [6].

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## 4. BEHAVIOURAL EPIDEMIOLOGY: MATHEMATICAL MODELS FACING THE COMPLEXITY OF MODERN SOCIETY

Although the description of the infection process, as in the chemical analogy above, is extremely intriguing, traditional mathematical models in the epidemiology of infectious diseases are not able to fully capture dynamics of spread in the modern world. Our modern societies have behaviours that are much more complex. Indeed, paradoxically in parallel with the development of the information age we the rise of the post-trust age [10], where citizens are less and less willing to behave according to the advice of public authorities, including those concerning the areas of the health.

In our age, classical mathematical models performs less well because human beings are not particles.

The investigation on the role of human behaviour in determining the spread of infectious diseases, both influencing the pattern of contacts at risk and the vaccination patterns have recently lead to a new discipline: behavioural epidemiology of infectious diseases [15].

As it frequently happens in science, this new discipline has old roots in seminal works that were not enough appreciated at their time of initial publication.

Indeed, as soon as the late seventies Capasso and Serio were the first to stress that the molecule-based modelling had to be modified



in order to capture the psychologic elements [11]. Moreover, they were also able to show that such a modification did not require a total rethinking to the previous modelling paradigm, but only a redefinition of parameters. In particular they stressed out that the probability of infection cannot be considered as constant but depending on the prevalence of the disease [11]. This must not be surprising because such probability does not only depend on biological and physical parameters (viral charge, temperature etc...) but also on human Thirty years later we have behaviour. elaborated more on this point: the probability of contagion depends on the available information (and rumours) on the prevalence of the disease [12].

Many years later from the seminal work by Capasso and Serio, another side of the behavioural response to the spread of an infectious disease was addressed: the propensity to vaccinate or to refuse vaccination [13.15]. Thus the fraction of children that are vaccinated is neither constant nor follows a temporal pattern defined by the PH authorities: instead, it depends on the behaviour and decisions of the children's parents. [13].

One of the results suggested by this type of modelling is that if vaccination for a certain disease is not mandatory, it is impossible to eradicate the disease by simply trusting on the good behaviour of population [13]. Moreover, models suggest that the effect of the above mentioned delays and "historical" memory of the past prevalence can trigger recurrent, but quite large epidemic outbreaks [13], larger than the statistical year-to-year fluctuations. Moreover, these models, often based on game theory [14,15], also suggest that although PH authorities are unable to impose mandatory vaccination, they can deliver/develop awareness campaigns that reduce the prevalence of the disease and can, under some certain conditions, lead to the eradication of the disease [14].

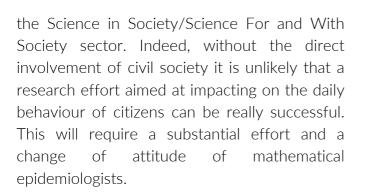
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# 5. CONCLUDING REMARKS AND PERSPECTIVES FOR SCIENCE IN SOCIETY/SCIENCE WITH AND FOR SOCIETY

Behavioural Epidemiology of Infectious Diseases is a growing discipline with a number of leading scientists involved in it [15], and its development is showing interesting results. In particular, it is clear that an interdisciplinary approach is needed that goes well beyond the traditional mixing between clinical and mathematical competences, as expressed in traditional biostatistics and biomathematics. Scientists working in this field have to develop both economics and sociology competences [15], as well as anthropological ones. Indeed, medical anthropology the approach is extremely useful to understand behaviour in very areas such as vaccine choice and personal habits. This is especially true, if it has to be applied in different geographical contexts, including, high income countries, where posttrust society is extremely diffused leading to high levels of opposition to vaccination.

However, Behavioural Epidemiology is now mature enough to pass to a second phase: the one where large scale projects need to be developed, in which representative samples of people have not only to be periodically questioned but also be directly involved. In other words, behavioural epidemiology of infectious diseases is a natural laboratory for





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