



## RISK, SURVEILLANCE AND SOCIETY

Sara Shaw

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When you have completed the reading and participated in the taught components for this week, we hope you will be able to....

Outline different approaches to thinking about and managing risk and the implications for health, illness and society.

Critically reflect upon the development of medical screening and the way in which it shapes the perceptions and experiences of health and illness.

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## The point of this lecture....

...is NOT to engage in discussion about the relative claims to truth of competing arguments about what phenomena should be considered 'real risks' or not

...is to look at the ways in which CONCEPT of risk operates in society and the implications

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**Four main areas:**

1. The rise of 'Risk Society'
2. Risk and culture
3. Risk and surveillance
4. Summary
5. Introduction to virtual seminar - medical screening

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**1. The rise of 'Risk Society'**

- Development of modern society
- Increasing significance of risk in society
- Relevance to health, illness and medicine

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**Pre-modern ideas of risk**



- Early use linked to maritime ventures
- Maritime insurance used to highlight an objective danger or an act of God.
- Risk was a natural event (e.g. storm)
- Human fault or responsibility excluded

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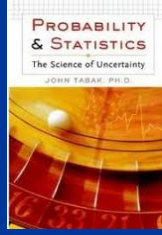
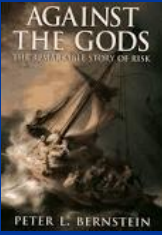
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## The mastery of risk



The future is more than the whim of the gods...  
men and women are not passive before nature

Bernstein, 1996 p1

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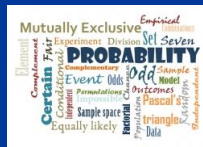
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## Modernity

(modern society, industrial civilisation)

- The key to human progress and social order is objective knowledge through scientific exploration and rational thinking
- Assumes that social and natural worlds follow laws that may be measured, calculated and therefore predicted
- Preoccupied with the future
- Science of probability and statistics key




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**THEORY.ORG.UK TRADING CARD**



**Ulrich Beck**

Beck is famous for proposing the idea of 'risk society' (first published 1986, in German). Risk is 'a systematic way of dealing with hazards and insecurities induced & introduced by modernization'. Because modern living is characterised by decision-making, risk assessment and management also becomes part of the everyday. More recently, Beck has developed ideas about reflexivity and the self in modernity alongside his friend Giddens. Fab.

See [www.theory.org.uk](http://www.theory.org.uk) and [www.theoryhead.com/gender](http://www.theoryhead.com/gender)

**STRENGTHS:** New ideas about modern living

**WEAKNESSES:** Like Giddens but not quite as readable

**SPECIAL SKILLS:** Pleasant, brilliant, Europe's finest




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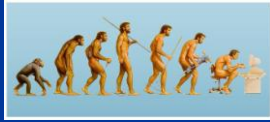
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## Risk Society

- Greater control over the risks posed by nature
- BUT new 'man-made' risks (e.g. nuclear power, pollution, global warming)
- Risk is the flipside of increased opportunities we have created through science and technology
- Opportunities for material, physical and social security BUT science and technology have a dark side.....



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## Techno-scientific approach to risk

$$R = PM$$

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What part does risk play in modern healthcare? Examples?



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## Risk in health and healthcare



The Risk Epidemic in Medical Journals: Numerical Data Tables

	Risk articles	Published articles	% Risk articles
<b>MEDLINE</b>			
1967-1971	990	1029289	0.1
1972-1976	6485	1160317	0.6
1977-1981	23190	1298885	1.8
1982-1986	44077	1487893	3.0
1987-1991	81586	1802671	4.5

Skolbekken, SSM 1995

- Medical and epidemiological journals
- US, UK, Scandinavia
- Increasing frequency of use of the term
- Late 1970s marks beginning of rapid growth
- Risk epidemic

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In 2001, the *British Medical Journal* decided to ban the word 'accidents'. Why do you think this was?



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## 2. Risk and culture

- Cultural theory of risk
- Risk and blame
- Lay perceptions and experience of risk

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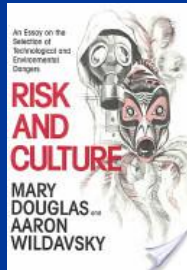
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## Cultural Theory of Risk

- Critiques realist, techno-scientific approach
- Examines how and why individuals form judgements about danger and threats
- Seeks to explain why some dangers are identified as 'risks' and others not
- Focus on social groups




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## Culture shapes lay understanding of risk

Individuals do not try to make independent choices...when faced with estimating probability and credibility, they come primed with culturally learned assumptions and weightings

Douglas, 1992: 58

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## Social response to risk



- Historical analysis
- Swine flu, Fukushima
- Use not driven by evidence
- Social response to risk of disease
- State, media and commercial pressures
- Individual responsibility




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# Risk and blame

**SOCILOGY OF HEALTH & ILLNESS**  
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**Who's to Blame? Accounts of genetic responsibility and blame among Ashkenazi Jewish women at risk of BRCA breast cancer!**  
 Jenica Mustersky

*Research Foundation, Wellcome, Fundational and United for the Regeneration of Genetic Research, University of Pennsylvania, Philadelphia, United States*

**Abstract** Genetic knowledge of cancer risk has enhanced access of public responsibility, whereby individuals are held liable for biological risk-choices. How and why individuals are held liable for genetic risk depends on their beliefs, their actions and their social group of origin. This research used public responsibility theory to explore how Ashkenazi Jewish women at risk of BRCA gene-related cancer. A research team interviewed 14 individuals in-depth to explore their accounts of genetic responsibility and of particular practices for cancer-prevention of breast cancer. Research team participants included genetic epidemiologists, genetic counselors, and lay individuals who had been interviewed in depth as part of an earlier study. This research was based on in-depth analysis of interview transcripts and published literature on genetic epidemiology and responsibility for cancer prevention. Findings reveal the complexities of genetic risk and the challenges of cancer prevention in a Jewish community. The research has implications for research on cancer prevention and health communication in Jewish communities.

**Keywords:** BRCA, breast cancer, Ashkenazi Jews, genetic responsibility, cancer prevention

**The genetic factor:** The quality of life and personal efficacy will vary in women of genetic origin. Some women will be prepared for the genetic inheritance that their parents passed on (Doris and Ross 2001: 81).

**Introduction:** One consequence of medical genetic knowledge which has revolutionized adherence to risk of cancer susceptibility is the ability to identify genetic risk. Research by Marmot et al. (2006), Lubkin et al. (2007), Hutter and Ross (2008), Rubinstein (2008), Sklar (2008) reveals increasing access to genetic testing, and the knowledge of how to use genetic testing to reduce cancer risk. The research team interviewed 14 individuals in-depth to explore their accounts of genetic responsibility and of particular practices for cancer-prevention of breast cancer. Research team participants included genetic epidemiologists, genetic counselors, and lay individuals who had been interviewed in depth as part of an earlier study. This research was based on in-depth analysis of interview transcripts and published literature on genetic epidemiology and responsibility for cancer prevention. Findings reveal the complexities of genetic risk and the challenges of cancer prevention in a Jewish community. The research has implications for research on cancer prevention and health communication in Jewish communities.

- Ashkenazi Jewish community
- 1 in 40 risk of carrying BRAC1 & 2 genes
- 14 in-depth interviews
- Past and present
- Mitigate blame through
  - Comparison with other groups
  - Focus on ultra-orthodox practices

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# Lay understanding of risk

- The way people talk about and understand risk is different
- People must make their own choices, but from an ever-extending array of possible risks, which must be understood and balanced.
- The healthcare profession is in a significant position in giving meaning to the public's concept of risk and risk factors

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**Table 2—Descriptions of risk in relation to the risk of an individual dying (D) in any one year or developing an adverse response (A)**

Term used	Risk range	Example	Risk estimate
High	≥1:100	(A) Transmission to susceptible household contacts of measles and chickenpox <sup>6</sup>	1:1-1:2
		(A) Transmission of HIV from mother to child (Europe) <sup>7</sup>	1:6
Moderate	1:100-1:1000	(A) Gastrointestinal effects of antibiotics <sup>8</sup>	1:10-1:20
		(D) Smoking 10 cigarettes a day <sup>9</sup>	1:200
Low	1:1000-1:10 000	(D) All natural causes, age 40 <sup>9</sup>	1:850
		(D) All kinds of violence and poisoning <sup>9</sup>	1:3300
Very low	1:10 000-1:100 000	(D) Influenza <sup>10</sup>	1:5000
		(D) Accident on road <sup>9</sup>	1:8000
		(D) Leukaemia <sup>9</sup>	1:12 000
		(D) Playing soccer <sup>8</sup>	1:25 000
Minimal	1:100 000-1:1 000 000	(D) Accident at home <sup>9</sup>	1:26 000
		(D) Accident at work <sup>9</sup>	1:43 000
		(D) Homicide <sup>9</sup>	1:100 000
		(D) Accident on railway <sup>9</sup>	1:500 000
Negligible	≤1:1 000 000	(A) Vaccination associated polio <sup>10</sup>	1:1 000 000
		(D) Hit by lightning <sup>9</sup>	1:10 000 000
		(D) Release of radiation by nuclear power station <sup>9</sup>	1:10 000 000

Calman K (1996) Cancer: science and society and the communication of risk. *BMJ* 313:799-802

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Lay experience of risk

**SOCIOLOGY OF HEALTH & ILLNESS**  
Journal of Health Sociology, 34(1): 33-50 (2009)

**The experience of risk: an ‘insurance of vulnerability’?**  
**Health screening and lay uses of statistical risk**  
**Chris Gillespie**  
Department of Sociology, Brunel University, Watlington Rd, Uxbridge, Middlesex, UK

**Abstract:**  
 In the last decade, the ‘rehabilitation’ of the lay person’s voice in the public sphere has become a central goal of policy-makers and practitioners. This has been achieved through a variety of means, including the development of participatory risk assessment and the use of ‘plain’ language in risk communication. However, the ‘rehabilitation’ of the lay person’s voice has been largely confined to the public sphere, where it is often treated as a ‘rehabilitation’ of the lay person’s voice in the public sphere. This paper examines the ways in which lay people experience risk, and how this experience is shaped by the ways in which risk is communicated to them. It argues that the ways in which risk is communicated to lay people are often shaped by the ways in which risk is experienced by them. This paper explores the ways in which lay people experience risk, and how this experience is shaped by the ways in which risk is communicated to them. It argues that the ways in which risk is communicated to lay people are often shaped by the ways in which risk is experienced by them.

‘Scientifically-derived statistical measures that are intended to tame randomness and provide certainty in managing risk, instead, produce uncertainty and anxiety in those to whom the statistic is applied’ (p194)

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*[Being at risk] impacts your sense of your mortality in a way that’s very subtle. Even though I don’t view these numbers as risky, just the fact that, okay, I’ve got this thing that’s not in the normal range...On the other hand, it’s a placeholder for mortality at some point, and there is going to be a time when I get something really bad. And I’m – it’s almost like an anticipation, okay, this is the first of what may be a series of ‘uh-ohs’ down the road, and I think that that – that impact is very subtle, but I think it’s real. I think it’s a real effect*

Marshall, PhD in Engineering, PSA test

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3. Risk and surveillance

- Rise of surveillance medicine
- Preventative medicine

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# Surveillance medicine

*Biography of Health & Illness, Vol. 11, No. 3, 2002, 322N-334N-339N, pp. 327-334*

**The rise of surveillance medicine**

**David Armstrong**

*Guy's and St. Thomas' Medical and Dental School, University of London*

**Abstract** Despite the obvious triumph of a medical theory and practice grounded in the empiricist, in vivo tradition based on the surveillance of normal populations can be identified as emerging in the twentieth century. This new surveillance medicine involves a fundamental reworking of the space of illness. This includes the problematisation of mortality, the unworking of the relationship between symptoms, signs and illness, and the breakdown of illness outside the temporal space of the body. It is argued that this new medical has significant implications for the construction of identity in the late twentieth century.

**Introduction**

Perhaps the most important contribution for understanding the advent of modern medicine has been the work of the medical historian Achille Mbembe (1975), who described the emergence of a number of diverse medical practices during the early and late nineteenth century, in itself, as identifying an earlier phase of 'Liberal Medicine' in which the classical training of the physician ceased to be dependent on any specific knowledge of illness. This gave way to Biologic Medicine when physicians began to address the problems of the practical management of illness, particularly in terms of the identification of the patient's symptoms. In its own time, Biologic Medicine, was replaced by Hospital Medicine with the advent of hospitals in Paris at the end of the nineteenth century.

Hospital Medicine was clearly an important revolution in medical thinking, also known as the Clinic, pathological medicine, Western medicine and biomedicine. It has survived and extended itself over the last two centuries to become the dominant mode of medicine in the modern world. Even so, a significant alternative mode of medicine can be identified as flourishing during the twentieth century around the observation of seemingly healthy populations.

© 2002 Blackwell Publishing Ltd, *Journal of the Philosophy of Health Sciences*, 100, London, UK

- 'the observation of seemingly healthy populations' (p393)
- Focus on what is considered 'normal'
- Blurring of the distinction between health and illness
- Ensuring healthy 'norms' are maintained

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*This atlas will help you to put health risks and death rates into perspective. Use it to compare cause of death and risks to health based on sex, age and region.*



<http://www.nhs.uk/Tools/Pages/NHSAtlasofrisk.aspx>

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# Governmentality

- Power typically thought of as a hierarchical, top-down power of the state
- But there are other forms of *social control* ... People play an active role in their own *self-government*
- Guided by social institutions, procedures, analyses and reflections

**THEORY.ORG.UK TRADING CARD**



**Michel Foucault**

French thinker, 1926-1984. Earlier work noted how social order is maintained as people learn to keep checks on themselves. Later work saw self-identity as an active project, influencing queer theory. In *History of Sexuality*, Foucault suggests power is not a fixed property held by certain groups, but is fluid and present in all interactions. Where power is exercised, resistance develops; this is a productive relationship.

For more, see [www.theory.org.uk/foucault](http://www.theory.org.uk/foucault) (Card 3 of 12)

**KEYNOTES: Model of power innovative and real-life**

**WARNING: Idiosyncratic reading of history... arguable**

**SPECIAL ORDER: Supply rejects and credits, creates new world**

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## Example: Preventive medicine

- Assessing risk of illness in individuals
- Risk assessed by 'surveying' populations and identifying what is and is not 'normal'.
  - Use of risk factors as (potential) causes of disease
  - Risk factors → diseases to be cured → treatment
- Expands possibilities for medical intervention
- Risk itself becomes a condition to be treated

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Should 'prehypertension' be treated?  
Who benefits and why?



- 'Borderline' or 'high normal' blood pressure
- New diagnostic category
- Potentially 1 in 3 adults (c50 million in the US)

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## 4. Summary and reflection

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**There's no getting away from risk!**

Medicine tends to adopt techno-scientific approach

Social context influences the way lay people understand and manage health risks

Key concepts: risk society, risk and culture, surveillance medicine

**Risk is not neutral**

Identification and management of risk play a significant role in medicine and healthcare

Risk is associated with ideas about choice, responsibility and blame

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How might you critique the key sociological approaches to thinking about risk?




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## 5. Introduction to the virtual seminar

### Thinking critically about medical screening

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## Two papers

**SOCIOLOGY OF HEALTH & ILLNESS**

**The sociology of medical screening, past, present and future**  
Natalie Lounsbury and Helen Elliott

**Abstract:** Medical screening is a complex and contested activity. It is a key component of the medical system and has become a central feature of public health. This paper examines the historical development of medical screening and its role in the construction of health and illness. It also discusses the implications of medical screening for the individual and society.

**SOCIOLOGY OF HEALTH & ILLNESS**

**Screening: mapping medicine's temporal space**  
David Armstrong

**Abstract:** The paper examines the role of screening in the construction of health and illness. It discusses the historical development of screening and its role in the construction of health and illness. It also discusses the implications of screening for the individual and society.

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## Virtual seminar discussion

- Read the set reading. Pick an illness or disease that is (or could be) screened for (e.g. breast cancer, Huntington's disease).
- Focusing on your example, write 200-300 words on what medical screening is, who it might benefit or harm and why. Post your text in the virtual seminar and review/reply to others' as they appear.

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## Medical screening

### POPULATION

- Breast cancer
- Colon cancer
- Prostate cancer
- Newborn screening
- Cervical cancer
- Tuberculosis

### ROUTINE

- Breast cancer
- Huntington's disease
- Child development
- Gestational diabetes

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## The point of this seminar....

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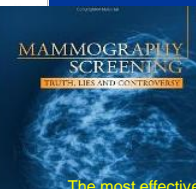
# Breast cancer screening

Breast screening, the verdict: it saves lives, but may also harm

The Guardian  
30 October 2012

Service saves 1,300 women a year • 4,000 undergo unnecessary

Home News U.S. | Sport | TV & Showbiz | Female | Health | Science | Money | Rightthink



The most effective way to decrease women's risk of becoming a breast cancer patient is to avoid attending screening

PETER C. GÖTZSCHE  
FORWARDED BY MAMMOGRAPHY

**Needless cancer therapy for 4,000 women: For every life saved by breast screening, three patients undergo unnecessary treatment**

- Nearly all are given aggressive treatments even though they might never have experienced any symptoms during their lifetime
- Treatments can involve months of agony and have severe impact on life
- Over 99 per cent of those diagnosed with breast cancer will have surgery
- Dilemma for doctors is that it is not possible to distinguish between those for whom disease could be fatal, and those who will never have symptoms

The Daily Mail, 30 October 2012

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Having a false positive result made her slightly anxious about the results of subsequent ...



**More about this person** **Print**

After I'd had my first scan, my first screening, I was called back. And that again was just another horrendous shock because I then again realised that I was vulnerable, it could happen to me.

He [consultant] explained that what they had seen on the x-ray were little, I think he said tea cup shapes or saucer shapes that were in the little shapes that showed up in the ducts and he, they were very concerned because that is where duct cancer or you know minute cancer cells germinate. But he was quite confident that they were, it wasn't anything to worry about.

And I think I asked a question, I think I asked about whether it was, would have been anything to do with breast feeding, because it was calcium dots, you know, episode of me [laughing]. I don't know, I can't remember what I asked, but I remember them being quite good about explaining what it was.

[http://www.healthtalkonline.org/Cancer/Breast\\_Screening/Topic/1210/](http://www.healthtalkonline.org/Cancer/Breast_Screening/Topic/1210/)

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## Critical reflection

- Balancing benefits / harms
- New roles and identities for patients
- Managing uncertainty
- Moral obligations
- Changing role of diagnosis
- Vested interests, commercialisation
- Medical screening elsewhere in the world

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