Tentative governance in the innovation journey of genomics and healthcare

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Content

- Medical genomics and healthcare
- The innovation journey
- Genomics and asthma research
- Future perspectives
Medical genomics and healthcare

- Emergence of medical genomics and healthcare
- Promises and expectations to future potential
- Interesting is the claim to a wholesale transformation
- What is the transformative potential of medical genomics for healthcare of common diseases?
The case of asthma research

- Assumption: early stage innovation process mainly taking place in science
- Focus on common disease research
- Analysis of 13 review papers (1999-2008)
- 9 interviews with asthma and/or genomics researchers
- How has genomics and asthma become linked?
The innovation journey

- Innovation journey is a nonlinear process, taking place in recognizable phases (Van de Ven et al. 1999)

(Sahal, 1985)
The innovation journey in context

- The innovation journey is the cross section of the overall co-evolutionary processes between technology and society (Rip and Schot 2002)

- Innovation journey refers to the emergence of underlying path-dependencies (Rip and Schot 2002)

- An emerging innovation journey is constructed in processes of de—and realignment (Rip and Schot 2002)
Emerging irreversibilities

- Investigation of emerging irreversibilities as a tool to follow the progress of the innovation journey

- Emerging irreversibilities; enable certain actions and cognitions while constraining others (Van Merkerk and Van Lente 2005; Van Merkerk 2008)

- Emerging irreversibilities can be traced through dynamics of expectations, agendas and actor arrangements (Van Merkerk and Van Lente 2005; Van Merkerk 2008)
A genomic future for asthma research?

- Initially genetics is presented as adding new insights to existing approaches (innovation journeys):
  
  - “The widely accepted paradigm is that environmental factors are important to the development of asthma, but one must be genetically predisposed to respond to environmental differences” (Los et al. 1999: 1210)
  
  - “Genetic studies of asthma continue to provide insight into the pathophysiological mechanisms of the disease” (Wiesch et al. 1999: 900)
An emerging innovation journey in asthma research

- Soon a new journey is taking shape:

- “Asthma genetics has finally crossed the line from a fledgling to a mature discipline. (…) The wave of the future of asthma genetics will probably include studies that combine the power of genetic and genomics approaches that use genome-wide SNP databases for gene searches and that tease out gene-gene and gene-environment interactions that are certainly involved in the manifestation of this complex disorder” (Wills-Karp and Ewart 2004: 385-86)
An emerging innovation journey in asthma research

“"This is an exiting time to be studying the genetics of asthma, with large-scale, collaborative, whole-genome association studies under way in the United States and Europe” (Moffatt 2008: 416).

“The identification of ADAM33 represented a breakthrough because this gene pointed to potentially new pathogenetic pathways for asthma“ (Vercelli 2008: 175)

“This ultimately will results in a deep understanding of the aetiology of previously mysterious diseases such as asthma, leading to the real potential of prevention and cures” (Moffatt 2008: 416).
The emergence of asthma/genomics innovation journey

▪ Effectively the new innovation journey is shaped through the dynamic of an emerging irreversibility

- Expectations: ‘deep understanding’, ‘real potential of prevention and cure’, ‘complete change in perspective’, ‘from a fledgling to a mature discipline’

- Actor arrangements: ‘Large-scale collaborative’

Transforming existing innovation journeys

- Definition of asthma:
  - Existing innovation journey where asthma is defined in terms of clinical manifestations
  - Transformed to a definition with emphasis on internal invisible gene-environment interactions

- Explanatory model:
  - Existing innovation journey where asthma is explained through the hygiene and allergen hypotheses
  - Transformed to a nonlinear endophenotype model of asthma’s
Resistance and uncertainty

- Resistance from participants in other innovation journeys:
  - “I think that genomics may become useful in certain diseases, but in highly complex diseases such as asthma (..) I think it will be impossible to find a batch of genomic testing that will reliably identify one phenotype or another” (asthma5 2009)

- In addition uncertainty is emerging if the asthma/genomics innovation journey will live up to its initial promises:
  - “I am more pessimistic than I was a few years ago” (asthma2 2009)
An emerging irreversibility within asthma research

Emerging irreversibility

Innovation journey of asthma research

Stabilising space

Branching moment

Asthma and genomics
Future perspectives

- Approach this uncertainty through discursive psychology

- Turn to asthma researchers themselves: How do they deal with this uncertainty?
  - What discursive practices are in use?
  - What interactional goals are achieved?
  - What are the implications for their own roles and responsibility?

- Investigate these discursive practices in interaction in an upcoming workshop
Thank you.

Comments are also welcome at:

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