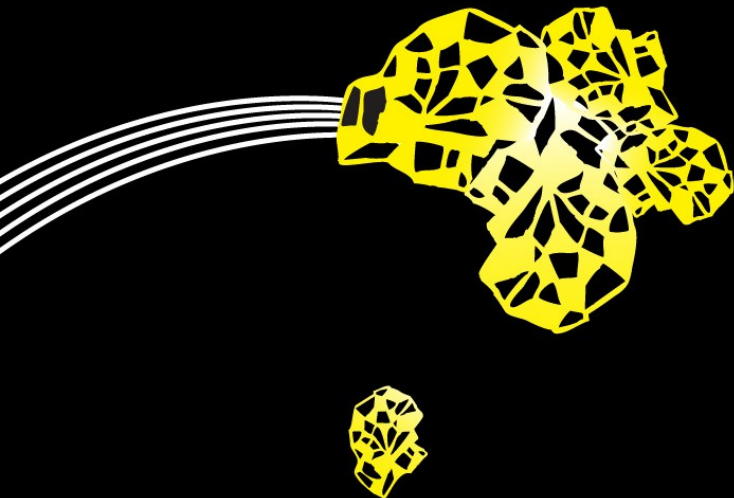
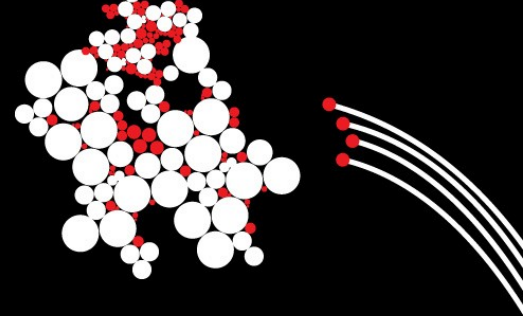


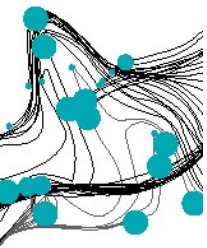
Tentative governance in the innovation journey of genomics and healthcare

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Centre for Society and Genomics



Presentation at the conference:
Tentative Governance in Emerging Science and Technology
October 28 2010 Twente University



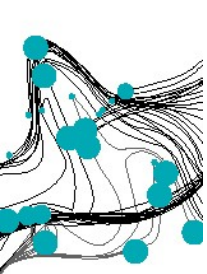


Content



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





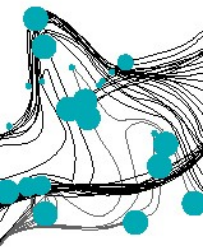
Medical genomics and healthcare



U.S. Department of Energy Genome Programs
<http://genomics.energy.gov>

- 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?

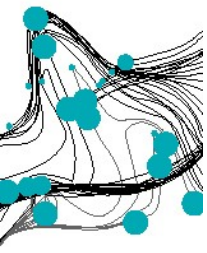




The case of asthma research

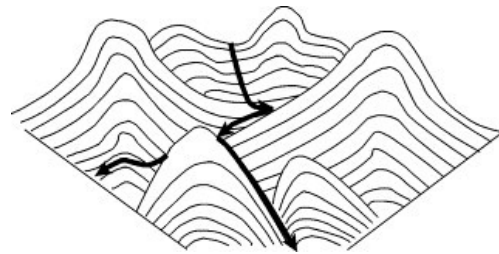
- Assumption: early stage innovation process mainly taking place in science
- Focus on common disease research
- Analysis of 13 review papers (1999-2008)
- 9 interviews with asthma and/or genomics researchers
- How has genomics and asthma become linked?





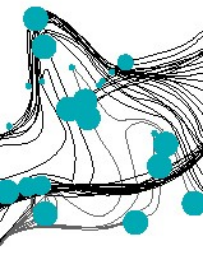
The innovation journey

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



(Sahal, 1985)



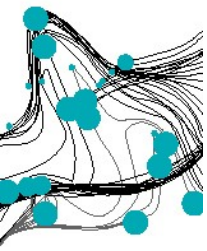


The innovation journey in context



- 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)



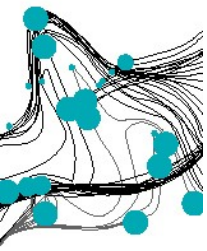


Emerging irreversibilities



- 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)

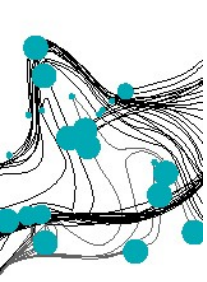




A genomic future for asthma research?



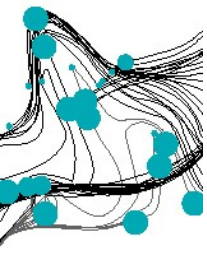
- Initially genetics is presented as adding new insights to existing approaches (innovation journeys):
- “The widely accepted paradigm is that environmental factors are important to the development of asthma, but one must be genetically predisposed to respond to environmental differences” (Los et al. 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)



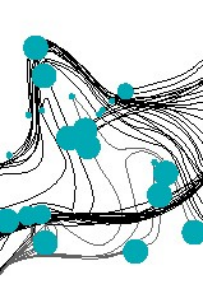


An emerging innovation journey in asthma research



- “This is an exciting 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 result 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).



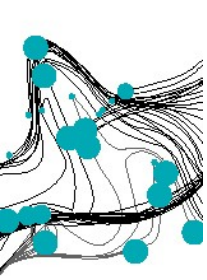


The emergence of asthma/genomics innovation journey



- 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’
 - Agenda: ‘Genome-wide association studies’, ‘omics’, ‘systems biology’



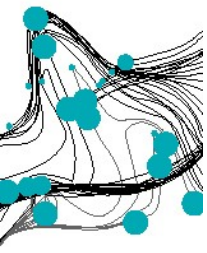


Transforming existing innovation journeys



- 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



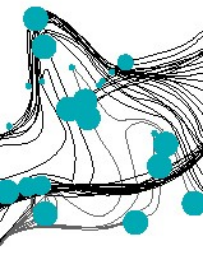


Resistance and uncertainty

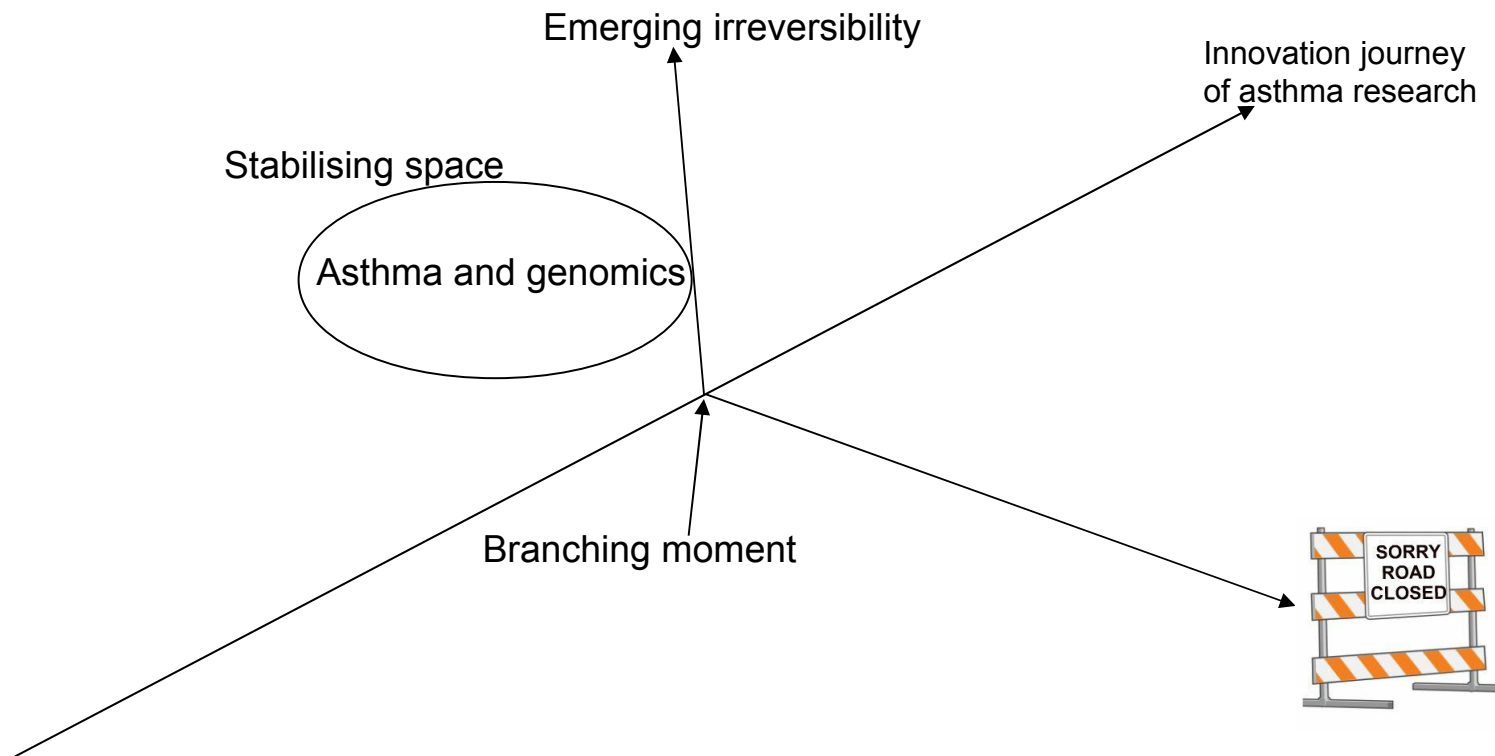


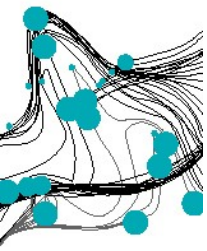
- Resistance from participants in other innovation journeys:
 - “I think that genomics may become useful in certain diseases, but in highly complex diseases such as asthma (..) I think it will be impossible to find a batch of genomic testing that will reliably identify one phenotype or another” (asthma5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

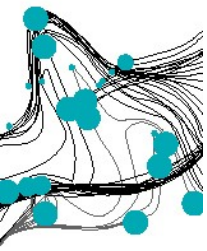




Future perspectives

- 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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