



SIMSAM, Challenges and possibilities for register-based research

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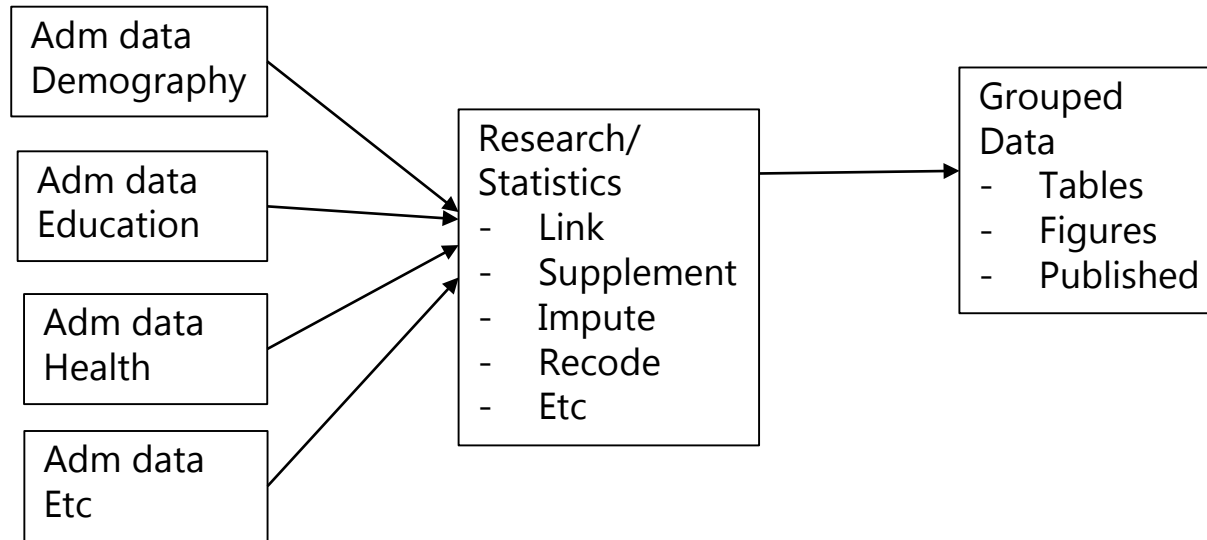
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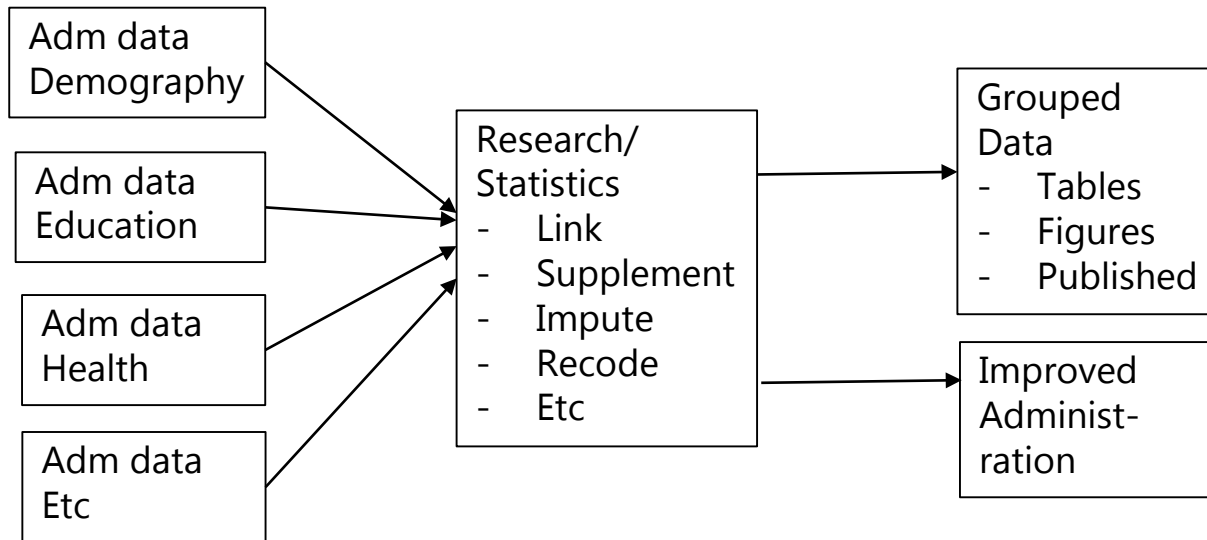


Register-based research as we know it



Use of common data for common good

Future challenges



Use of common data for individual good/social control

Future challenges - examples

- Personalized medicine: Use common data to find optimal treatment for given *patient* – but method common good
- Breakdown of traditional barrier between research/statistical and administrative data, recent examples from Denmark:
 - Mandatory, individual, questionnaire-based surveys in school classes about well-being: used to develop “concern-schemes” for individual pupils
 - Individual education data from Statistics Denmark used for administration of new work place training program
- Challenge: We can lose public trust in research/statistics
- Demand for informed consent to use register data, e.g. opt out option in new Danish law on National Genome Centre
- Register-based research as a *common* good – how can we defend it?



Thank you

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