

Using data for policy: Why and How to?

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Schweizerische Eidgenossenschaft
Confédération suisse
Confederazione Svizzera
Confederaziun svizra

Federal Department of Home Affairs FDHA
Federal Office of Public Health FOPH
Prevention and Healthcare Provision Directorate

Health Equity Forum
«Equity in health care: new insights and challenges»

Online conference, Thursday, 1st December 2022, 01:00 pm - 5:30 pm

Public policy

= government actions to establish, pursue and achieve goals.

= “Anything a government chooses to do or not to do.”

(Thomas Dye 1972 Understanding Public Policy)

Determinants

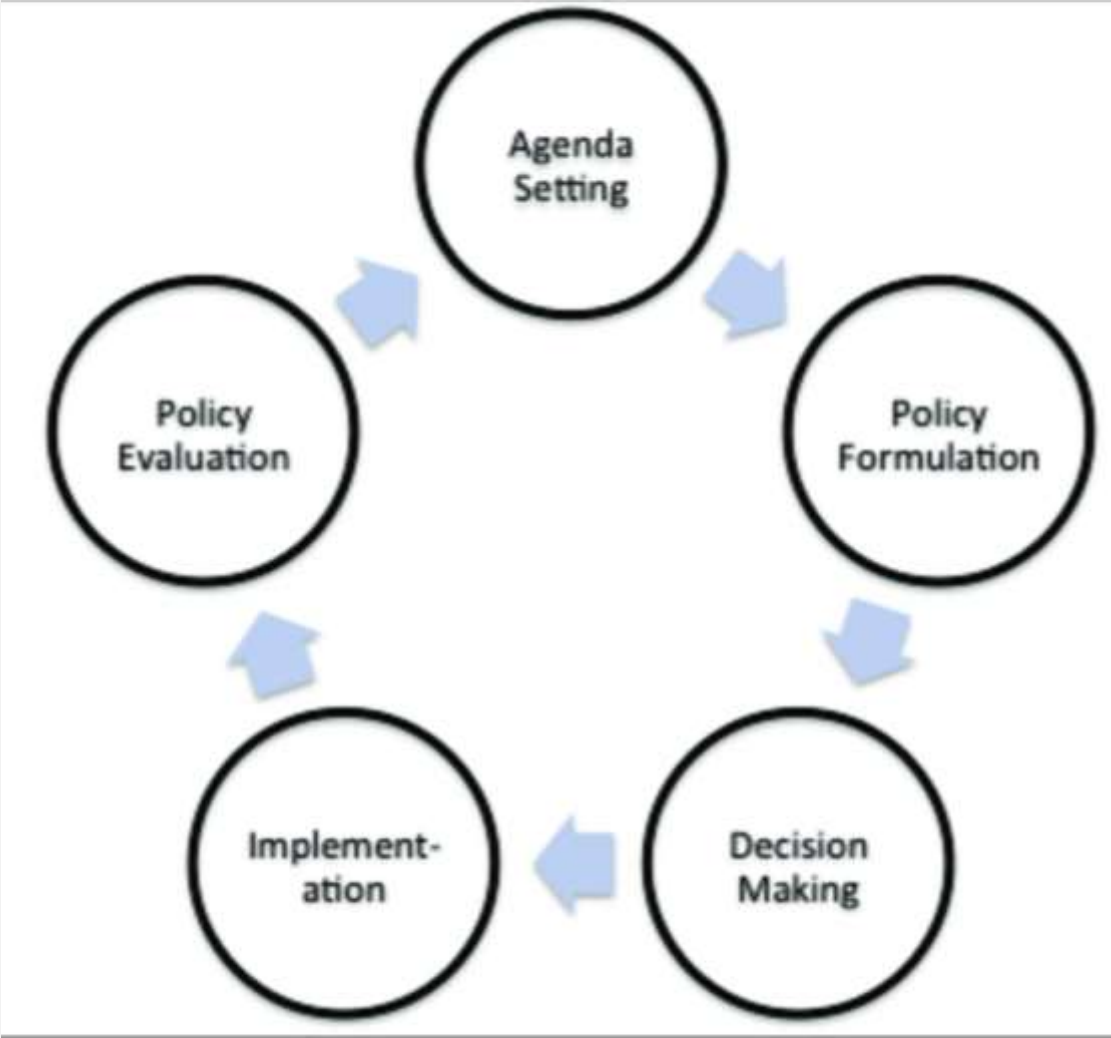
Personal experience/intuition, ideology, religion, economics, environment, institutional design, public opinion.



Background

Policy Process

Policy Process Stages



cycle model (after Howlett and Ramesh 1995)

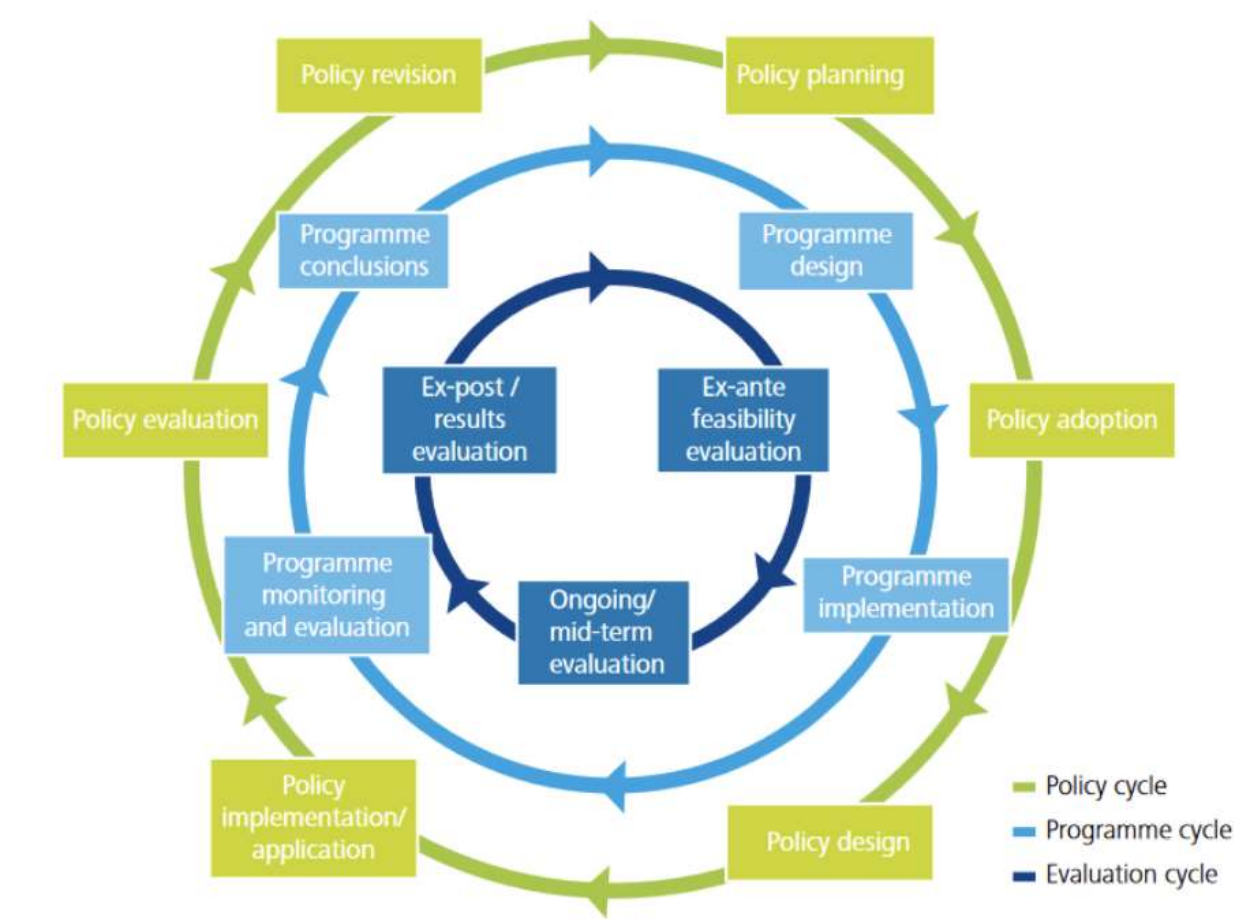


Figure 3 - Better Regulation Strategy Policy Making Cycle

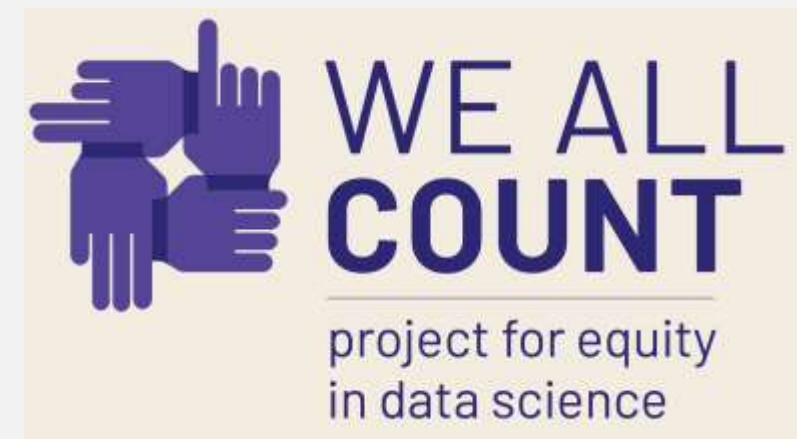
Government Data Collection and Use

- widely established, enduring, and extended history increased in importance over time:
 - First census,
 - ~6000 years ago, Babylonia
 - 1665, Modern census Quebec Canada (part of France at time)
 - 1790, USA Constitution-based (Art. 1, Section 2)
 - 1850, Switzerland

DID YOU KNOW?

Every census is a survey, but not every survey is a census.

Policy Implications



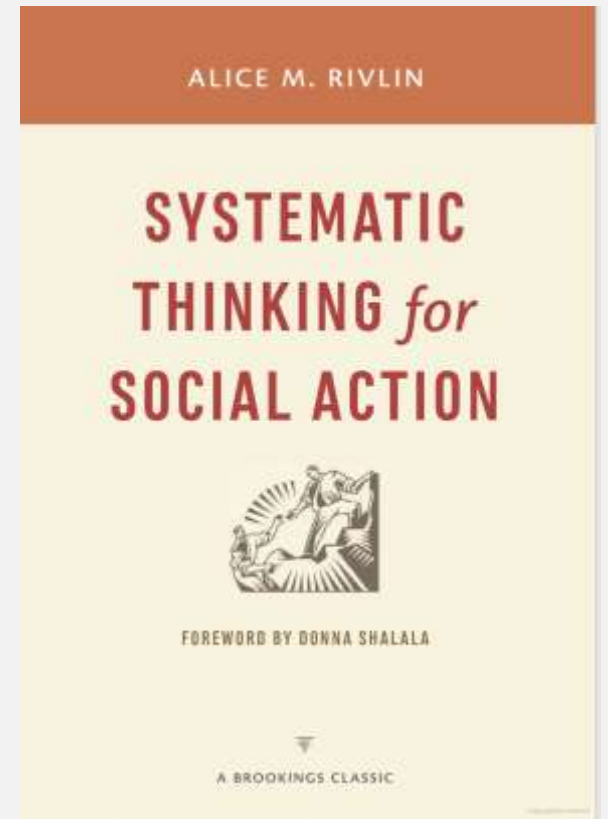
- Slaves were included in the US census
 - anti slavery groups (1850s) used U.S. Census data to demonstrate slave population were increasing
- Indigenous people were excluded from U.S. Census until 1860
- Supreme Court said that the census is the **“linchpin of federal statistical system”**
 - **“plan to use two forms of statistical sampling in the 2000 Decennial Census to address a chronic and apparently growing problem of “undercounting” of some identifiable groups, including certain minorities, children, and renters.”**



Why to?

“To do better we must have
**a way to distinguish better
from worse.**”

(Alice Rivlin, 1970)



Improved decision making

- “Data driven applications will benefit citizens and businesses in many ways.
 - improve health care
 - create safer and cleaner transport systems
 - generate new products and services
 - reduce the costs of public services
 - improve sustainability and energy efficiency”



European Strategy for Data:

<https://digital-strategy.ec.europa.eu/en/policies/strategy-data>

Policy Reasons for Data Use

- Problem Description (identification, distribution, patterns, trends, duration)
- Prioritisation of problems
- Precision (person, time, location, issue, policy)
- Policy design, simulation
- Policy evaluation
- Policy modification
- Enhanced management, planning and strategic capacity
- Cost effectiveness
- Predictive
- Transparency
- Public Trust and confidence





How to?

How to?

Data use challenges

Data Access and Utilization

Changing Data Needs

Insufficient Data

Data Access and Utilization





Inter-university Consortium for Political and Social Research (ICPSR)
National Endowment for the Arts, National Center for Health Statistics, National Science Foundation, US Agency for International Development among many government sponsors. Nearly 18 000 studies, 6 million variables.

<https://www.icpsr.umich.edu/web/pages/>

gesis

Leibniz Institute
for the Social Sciences

 [Deutsch](#)



Tools ▾ Training ▾ Strategy & Expertise ▾ Development & Impact ▾

Consortium of European Social Science Data Archives

Data Catalogue contains descriptions (metadata) of more than 40,000 data collections from over 20 European countries. <https://www.cessda.eu/Tools/Data-Catalogue>



An initiative of the Swiss Government

The Swiss Personalized Health Network is a national initiative under the leadership of the Swiss Academy of Medical Sciences (SAMS). In collaboration with the SIB Swiss Institute of Bioinformatics it contributes to the development, implementation and validation of coordinated data infrastructures in order to make health-relevant data interoperable and shareable for research in Switzerland.

European Cancer Inequalities Registry

The European Cancer Inequalities Registry is a flagship initiative of Europe's Beating Cancer Plan. It provides sound and reliable data on cancer prevention and care to identify trends, disparities and inequalities between Member States and regions

Cancer concerns us all in one way or another. It has important impacts on patients, but it also severely affects the lives of their families and friends. In 2020, it is estimated that 2.7 million people in the European Union were diagnosed with the disease, and another 1.3 million people lost their lives to it. Unless we take decisive action now, in the EU by 2040 new cancer cases are set to increase by 21%, while cancer deaths by 31%.



Building infrastructure to integrate and harmonize data from different sources and on different scales.

<https://globalhealthequity.umich.edu/data-harmonization-and-vaccine-hesitancy>



HEALTH INEQUALITY MONITOR ▾

Health Inequality Monitor

Explore health inequality monitoring evidence, tools, resources and training

[Home](#) / [Data](#) / [Health Inequality Monitor](#) / [Data](#)

Data Repository

Data for variety of topics, downloadable (.xls format), HEAT tool for analysis) https://www.who.int/data/inequality-monitor/data#PageContent_C158_Col00

Changing Data Needs

Collection of high-quality data disaggregated across various dimensions (e.g., age, sex, ethnicity, disability, geography) is a

“key [step] to making decisions and monitoring progress in achieving sustainable development for all”.

“a shift away from aggregate *broad trend kind of information* to trying to get more integrated granular information **that can really lead to localized solutions.**”

Haishan Fu
Director, Development Data Group,
World Bank



<https://ieg.worldbankgroup.org/news/role-of-data-in-policy-making>

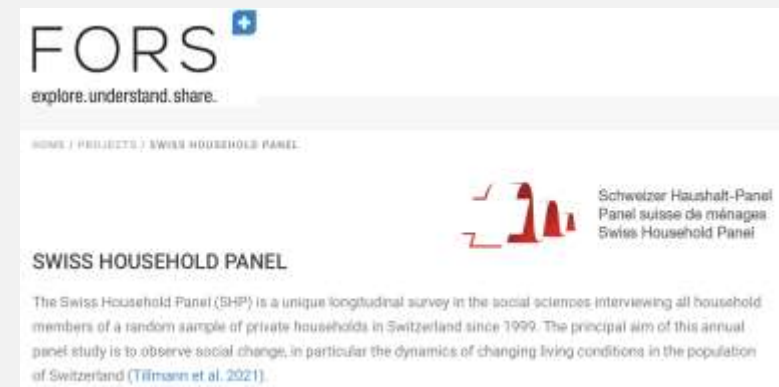
Insufficient data



Swiss Household Panel Switzerland

- longitudinal annual survey interviewing members of a random sample of private households since 1999 to observe social change, living conditions.
- Possible to merge data files (from several years, combining individual and household information or combining data from couples/families),
- model syntaxes are available.
- “SWISS Household Panel SHP Wave 22 - modules on Social participation and Political behaviour and values, **and three new question on feelings towards LGBTIQ** individuals.

<https://forscenter.ch/projects/swiss-household-panel/>

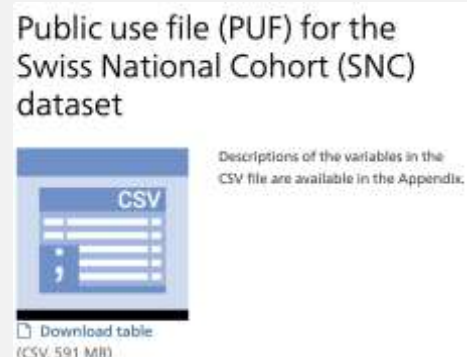


The screenshot shows the FORS website. At the top, the FORS logo is displayed with the tagline "explore. understand. share." Below this, a navigation bar includes "HOME / PROJECTS / SWISS HOUSEHOLD PANEL". The main content area features the project title "SWISS HOUSEHOLD PANEL" in bold, accompanied by a red logo of a house with a plus sign. To the right, the project name is written in three languages: "Schweizer Haushalt-Panel", "Panel suisse de ménages", and "Swiss Household Panel". A descriptive paragraph follows, stating: "The Swiss Household Panel (SHP) is a unique longitudinal survey in the social sciences interviewing all household members of a random sample of private households in Switzerland since 1999. The principal aim of this annual panel study is to observe social change, in particular the dynamics of changing living conditions in the population of Switzerland (Tilman et al. 2021)." The FORS logo and tagline are repeated at the bottom of the page.



Swiss National Cohort (SNC)

- Swiss National Cohort - Public Health Institutes (Basel, Bern, Zurich) funded by SNSF, Managed by FSO.
- Integrates various data sets for public health research, census data (1990, 2000), Registry-based census, annual structural surveys from 2010.
- Enables public health research in combination with other longitudinal or environmental data



“A public use file is available to you. Please consult the tab «Methodology» at the bottom of this page.”

How to?

Data Policy

Policy related to the authorization, funding, collection, access, communication, reporting, storage, archiving, distribution of data (typically raw data)

Switzerland Health2030 Strategy

- “The Federal Council wishes to promote digitalisation and the use of data...

- Health data are important, for
 - **medical research**
 - **efficient and optimal organisation of healthcare,**
 - **and for maintaining and improving public health...**



- Digitalisation in the health system must be coordinated between partners and allow the multiple use of data and infrastructures.”

European Union Data Policy

- “first proposal of domain-specific common European data spaces.
- will address health-specific challenges to electronic health data access and sharing, is one of the priorities of the European Commission in the area of health...
- **make it possible for researchers, innovators and policy makers to use this electronic health data in a trusted and secure way that preserves privacy.”**

Strasbourg, 3.5.2022

COM(2022) 197 final

2022/0140(COD)

Proposal for a

REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL

on the European Health Data Space

USA: Evidence-based Policymaking Policy

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THE WHITE HOUSE



JANUARY 27, 2021

Memorandum on Restoring Trust in Government Through Scientific Integrity and Evidence-Based Policymaking

 BRIEFING ROOM  PRESIDENTIAL ACTIONS

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How to?

Policy data

Administrative data, related to specific policy, measures of population, economy, health, environment etc. Traditionally produced by government, academic, research organizations.

Useful to measure, assess, compare, evaluate policy

Switzerland: Legislature Indicators

- Uses administrative data
- Benchmarks progress on policy goals
- Created by the Federal Statistical Office at the request of the Federal Chancellery
- “from a monitoring system that encompasses all areas of federal tasks...52 legislature indicators were selected.
- To observe the objectives defined by the Federal Council and Parliament, and drafting the situation analysis in the Federal Council's annual report.”

Differenze salariali tra donne e uomini

Differenza salariale* tra donne e uomini rispetto al salario mensile lordo degli uomini, settore privato



* Valori in base al salario mediano

Fonte: UST- RSS

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WHO Policy Data

- “Inequalities can be assessed through disaggregated data and summary measures of health inequality, visualized in interactive graphs, maps and tables.”



Health equity policy data

- “European Health Equity Status Report initiative (HESRI) is being developed as a mechanism to promote and support policy action and commitment for health equity and well-being in the European Region.
- **to shift political and policy focus from describing the problem to capturing progress and enabling action to increase equity in health.”**

Table 1. Health Equity Policy Tool: policy action areas and their definitions

Policy action area	Definition
Health services	Policies that ensure the availability, accessibility, affordability and quality of prevention, treatment and health-care services and programmes
Income security and social protection	Policies that ensure basic income security and reduce the adverse health and social consequences of poverty over the life-course
Living conditions	Policies that equalize differential opportunities, access and exposure to living conditions and environmental factors that impact our health and well-being
Social and human capital	Policies that improve human capital for health through education, learning and literacy; and policies that improve the social capital of individuals and communities in a way that protects and promotes health and well-being
Employment and working conditions	Policies that improve the health impact of employment and working conditions, including availability, accessibility, security, wages, physical and mental demands, and exposure to unsafe work



The Health Equity Policy Tool covers two types of indicators in each policy action area:

1. measures of the **implementation** of and **investment** in policies promoting health equity; and
2. measures of the **equity impact** of policies addressing the determinants of health or their consequences.



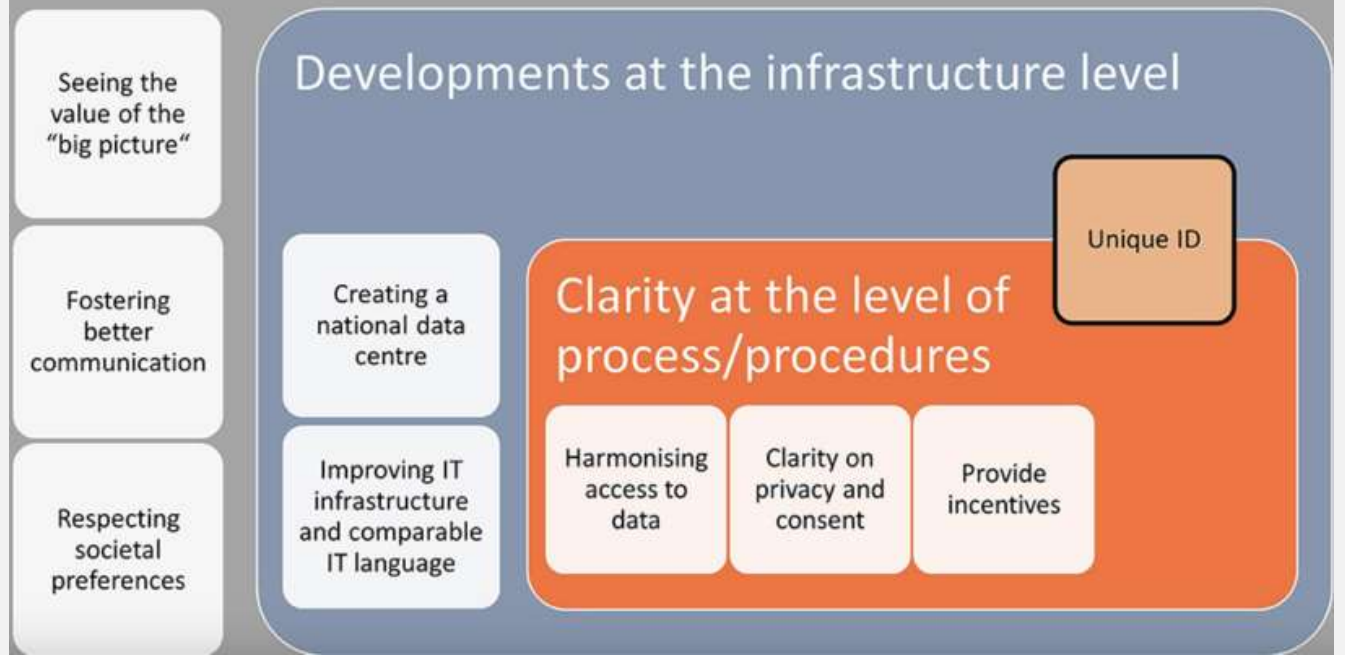
**A good step for
Switzerland**

Evolution or Revolution? Recommendations to Improve the Swiss Health Data Framework

 Andrea Martani^{1*},  Lester Darryl Geneviève¹,  Sophia Mira Egli²,  Frédéric Erard³,

 Tenzin Wangmo¹ and  Bernice Simone Elger^{1,4}

Changes at the level of mind-set and attitudes of engaged stakeholders



Recommendation

Concrete implications

Seeing the value of the “big picture”

→ a clear health data strategy must be developed: this includes agreeing on the important objectives that need to be achieved by collecting and processing health data.

Fostering better communication

→ ensure that different actors are continuously engaged in a proactive exchange: institutions and initiatives in the health data framework have to be known by all actors to coordinate efforts.

Respecting societal preferences

→ the development of the health data framework has to combine efficiency with considerations for population preferences and attitudes.

Changes a
stakeholder

Seeing the
value of the
“big picture”

Fostering
better
communication

Respecting
societal
preferences

Changes at the level of stakeholders

Seeing the value of the "big picture"

Fostering better communication

Respecting societal preferences

Development

Creating a national data centre

Improving IT infrastructure and comparable IT language

Recommendation

Create a national data centre

Improve IT infrastructure and promote comparable IT language

Unique Patient Identifier

Concrete implications

→ create an institution or an organisation that is capable of coordinating and combining the requests for data access and data linkage for the healthcare and research sector.

→ invest on a IT infrastructure that allows an effective reuse of health data. Also, ensure that data from different datasets are compatible by promoting the use of standard nomenclatures and formats

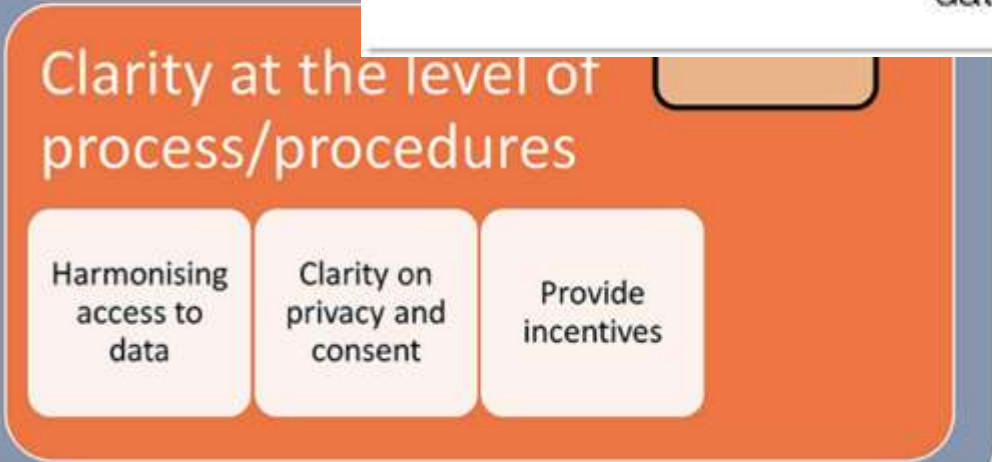
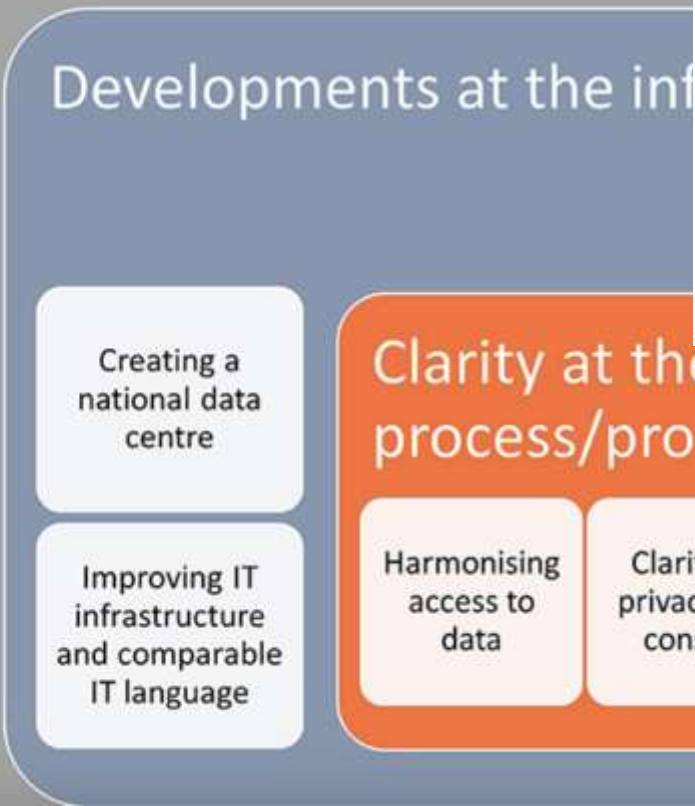
→ in a decentralised system like Switzerland, a unique identifier to link data concerning the same person from different sources should be enabled.

Changes at the level of mind-set and stakeholders

Seeing the value of the "big picture"

Fostering better communication

Respecting societal preferences

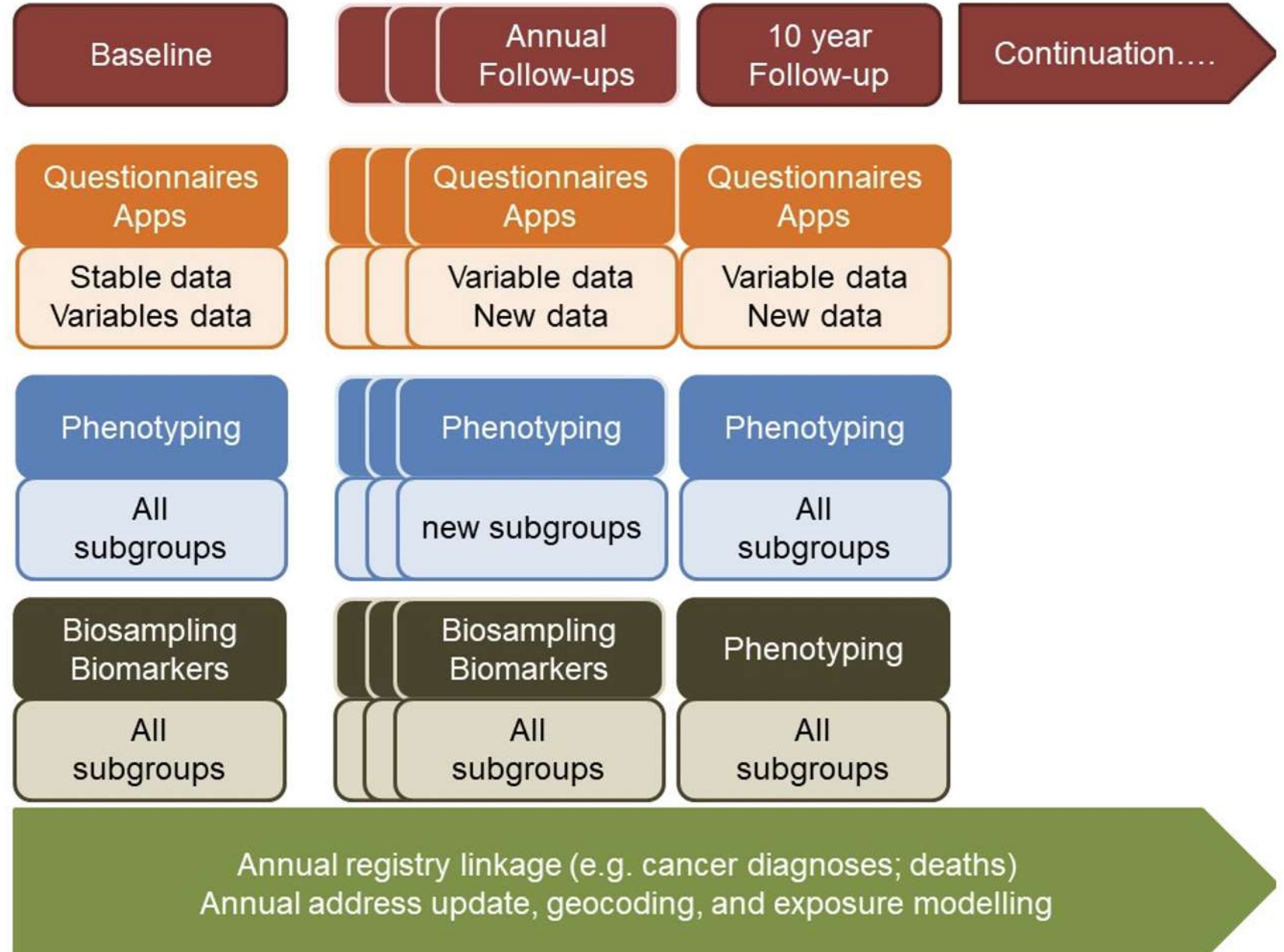


Recommendation	Concrete implications
Harmonise access to data	→ ensure that access procedures to data are less fragmented and dispersed, to facilitate the identification of data sources and the transparency of the process to obtain access to such data.
Clarity on privacy and consent	→ educate researchers on the data processing legal rules and implement more broadly a simplified pathway to allow the reuse of health data with more relaxed consent requirements.
Provide incentives	→ create tools to favour the cooperation between the different institutional actors that need to collaborate in the fulfilment of the procedures for data sharing and access.

Martani, A., et al., (2021). Evolution or Revolution? Recommendations to Improve the Swiss Health Data Framework. *Frontiers in Public Health*, 9, 668386. <https://doi.org/10.3389/fpubh.2021.668386>

Swiss Cohort & Biobank

– under consideration now



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