



Nacionalni inštitut  
za javno zdravje

# RESEARCHERS' ACCESS TO HEALTH DATA – FACTS AND CHALLENGES

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- Legal background for data collection and researchers' access
- How do we deal with researchers' requests?
- Structure of past requests
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# Short presentation of NIJZ and health data (1)

- Main role of National Institute of Public Health:
  - Data analyses in the field of public health, health system utilisation, preparation of evidence-based health policies
  - Health data collection, processing and dissemination
- There are some other (minor) health data providers in Slovenia (Cancer Registry).
- Other countries: similar situation, in most of the cases, the data are not strictly centralized

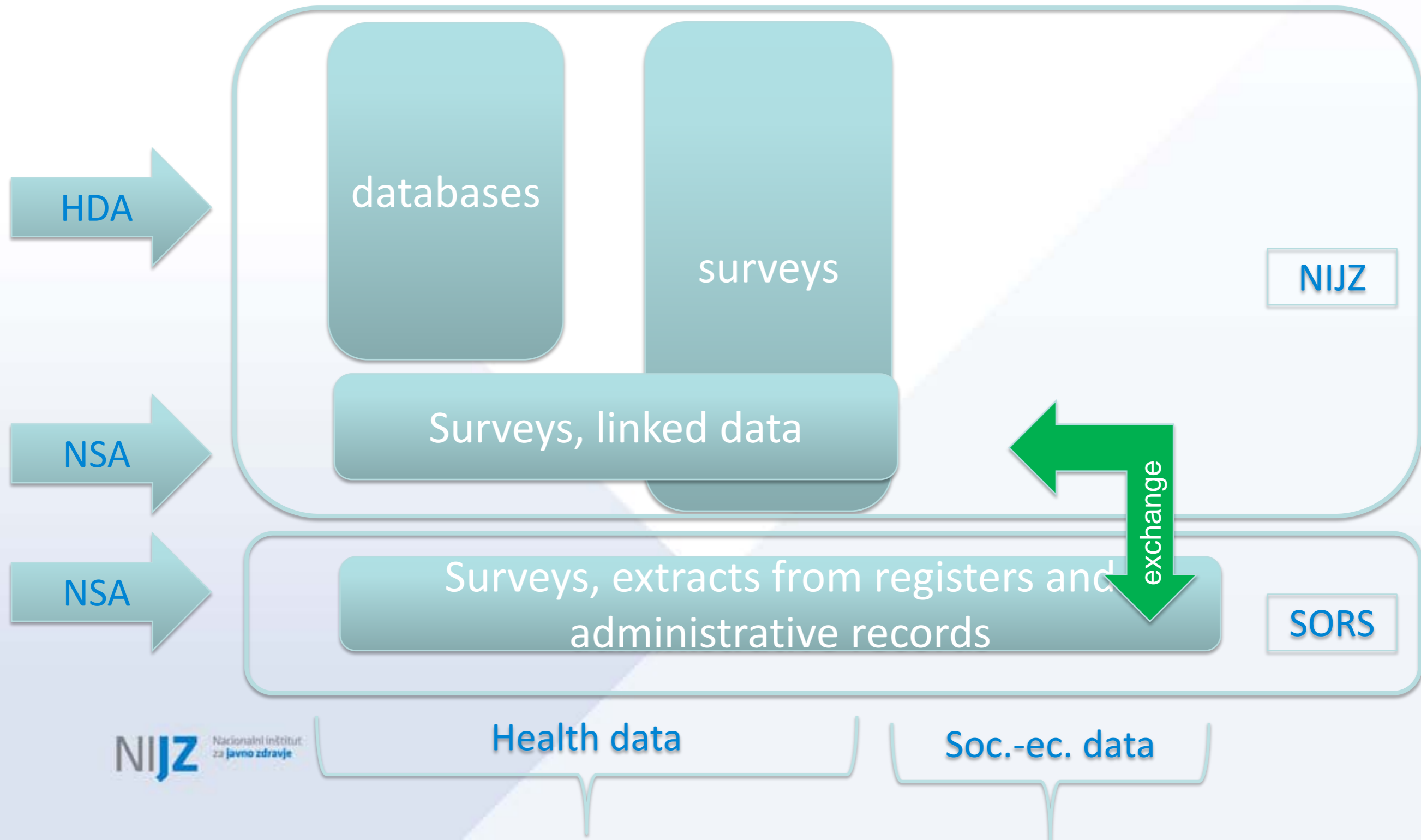
# Short presentation of NIJZ and health data (2)

- Most important registries and databases are:
  - Causes of Death Registry
  - Birth Registry
  - National Hospital Health Care Statistics Database
  - Absence from work due to medical reasons
  - Injuries at work
  - Prescription Database
  - Foetal Death Registry (abortions)
  - Database on Out-patient visits
  - First Treatment Demand – Drug users
- !!! Sensitive personal data

# Legal background

- Healthcare Databases Act (*HDA*, OG 65/2000)
  - Definition of all major health databases
- National Statistics Act (*NSA*)
  - Annual Program of Statistical Surveys
  - Enables linking of different data sources for statistical / research purposes
- Personal Data Protection Act

# Health data in Slovenia



# Legal background – access for researchers

- There is no distinction between the data sources, collected on the basis of HDA and the sources, used or compiled by NSA.
- National Statistics Act ([NSA](#))
- European Statistics Code of Practice
- Personal Data Protection Act

# Are health data different?

- Sensitive personal data
- Lots of different sets of data at hospitals and clinics
- Importance of cohort analyses
- Role of medical doctors („can see the data by definition“)
- Role of Medical Ethics Committee

In general, NO!



# How do we deal with researchers' requests?

# Rules of Procedure

- Internal Rules of Procedure
  - Internal Data Protection Committee
  - Important role of Head of Health Data Centre (responsible for data protection and security, decision-maker in case of unambiguous requests)
- Form for researchers' request available at our web site
- In majority of cases, the decision is made within 10 days, the data are prepared immediately.

# Our demands

- Status of researcher or research organisation
  - No industry (marketing, pharmaceutical,...) can get access to microdata.
- Need-to-know-principle
- Clear definition of request
- **IMPORTANT:** approval of National Medical Ethics Committee is important for researchers, but not required for data access. On the other hand, approval of Ethics Committee is not a guarantee to get the data!

# Mode of access

- Safe centre at the premises of NIJZ (Ljubljana)
- CD
- Remote access – hosting at SORS's infrastructure

# Structure of past request

# Structure of past requests (1)

## WHAT

- The most important databases: Causes of Death, National Hospital Health Care Statistics Database, Birth Registry, different surveys

## HOW

- Three types of requests:
  - Single dataset (e.g. Health Interview Survey)
  - Linked datasets (e.g. Causes of Death Registry linked to Registry on Hospitalisation)
  - Analyses of known cohort of patient

## WHERE FROM

- National, EU MS, EU-project connected, Eurostat, out of EU (e.g. USA)

# Structure of past requests (2)

- Linkage: performed by NIPH exclusively
- Access to linked data in the case of cohort analyses is judged case by case

# Conclusions



# Good / best practice

- Flexibility
- Fast response to researchers
- Possibility of using SORS's infrastructure
- Data linkage at single point
- Being part of the statistical system

# Challenges

- Analyses of data held at different institutions in the country (data linkage)
- Requests from non-researchers (e.g. Chamber of Pharmacy)
- Requests from abroad
- Utilisation of heaps of data within health systems
  - standardisation
- Upgrade of remote access
- Role of ethical committees

Thank you!

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