Enhancing secondary use of health data across the Nordic countries:

The Nordic Commons project
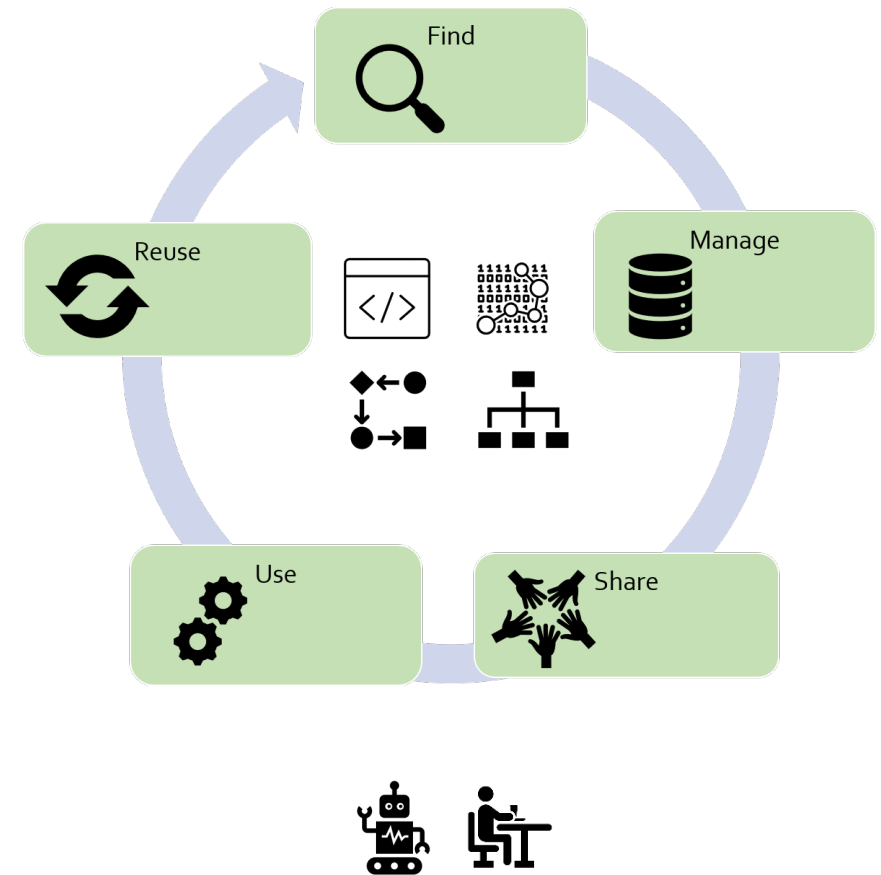
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What is a Nordic Data Commons?

o The **Nordic Commons** is a virtual space where scientists can

- **find** health data
- understand its **meaning**
- understand how it could be **used and re-used**
- have access to the right **software** and **services**
- **link** data from different sources
- use data at the **Nordic** level
- work in a **secure environment**
- ...according to **legal** and **ethical frameworks**

o **FAIR** data and data management is central – (meta)data
should be **F**indable-**A**ccessible-**I**nteroperable-**R**eusable

Nordic Strenghts

o   Each Nordic country have similar health data sources collected by health care, authorities, research and patients/individuals

o   Population-based, longitudinal data

o   Church and land records since 1600's

o   Register-, biobank-, genomics-, survey data

o   The personal identification number allows linkage

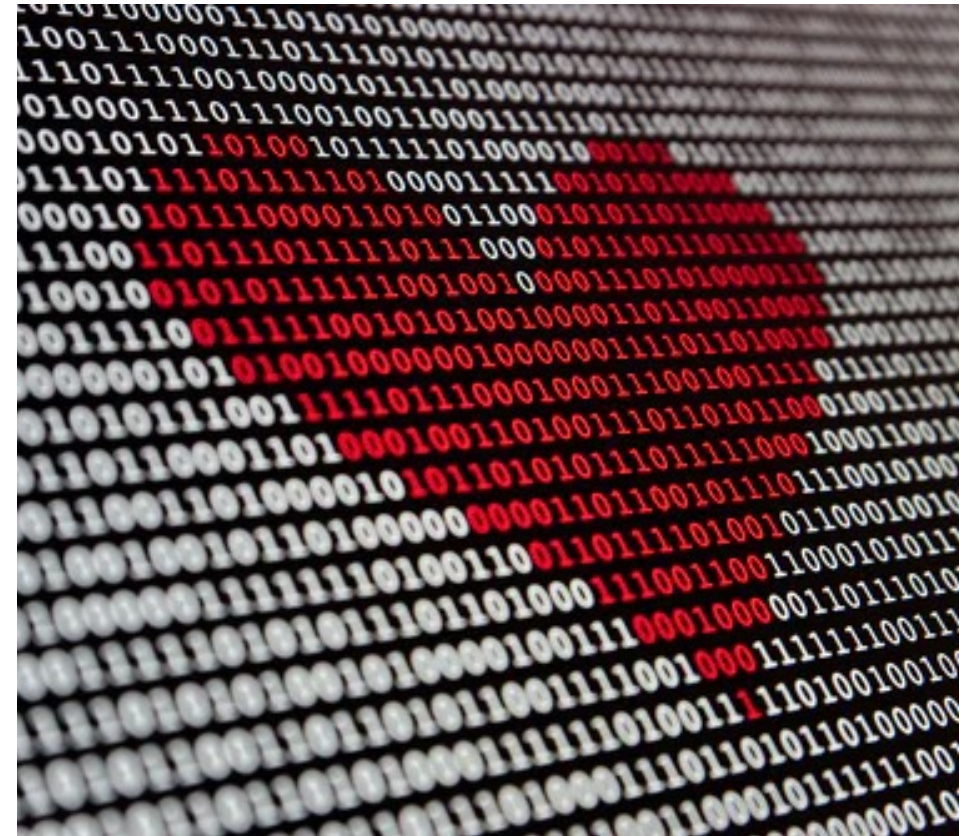o   Data "*from the cradle to the grave*"

o   Welfare state enables **trust**

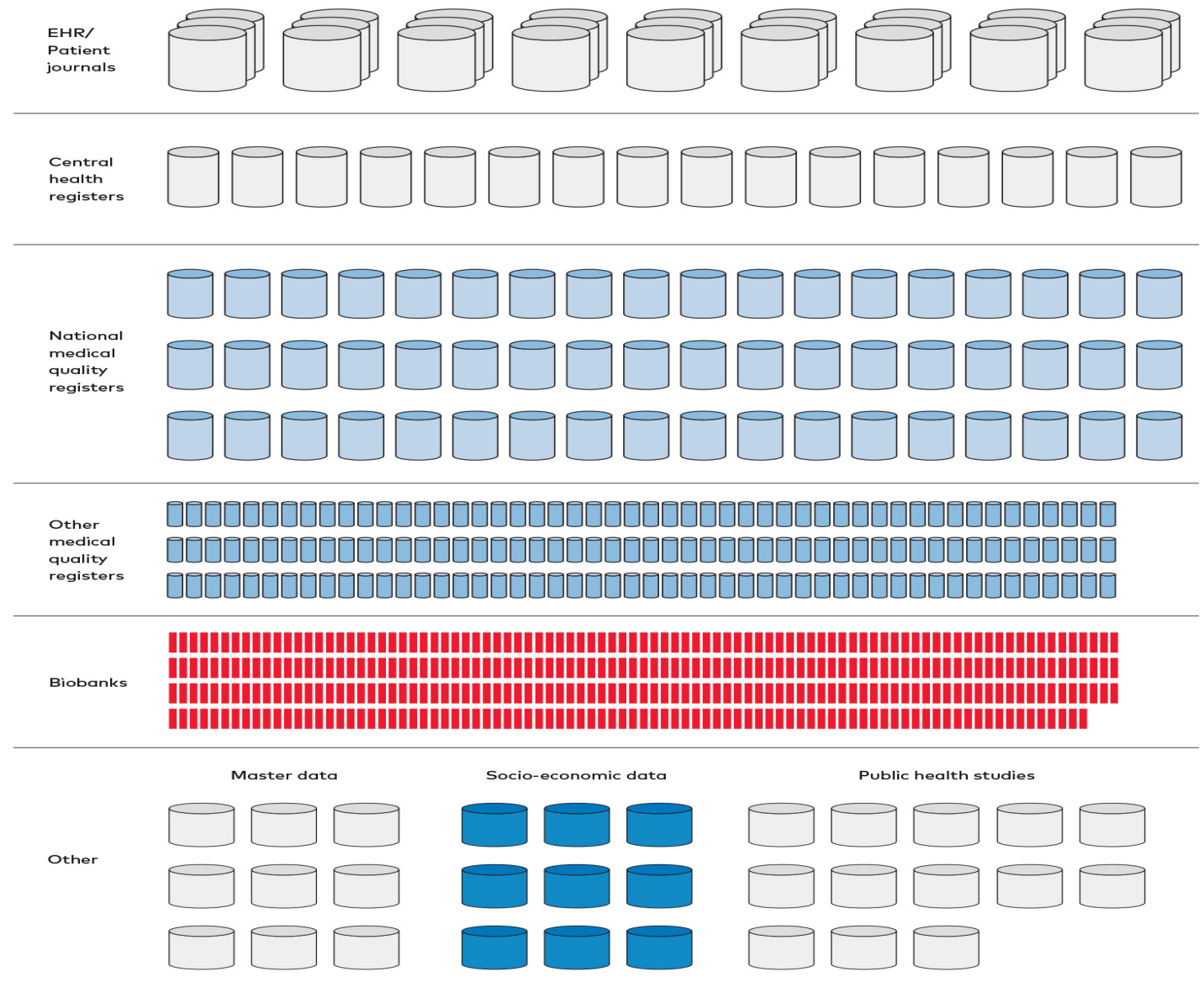

Photo by Alexander Sinn on Unsplash

Similar health data sources in each country for secondary use in research and innovation

Data producers
- authorities
- health care
- research
- patients/individuals

Data types
- register
- biobank
- genomics
- survey
- other health data

EHR/Patient journals

Central health registers

National medical quality registers

Other medical quality registers

Biobanks

Other

Master data

Socio-economic data

Public health studies

The Nordic reports during 2010's

Reinforced Nordic collaboration on data resources
Challenges from six perspectives

Joint Nordic Registers and Biobanks
A goldmine for health and welfare research

Det framtida nordiska hälsosamarbetet
Bo Könberg

PERSONALISED MEDICINE IN THE NORDIC COUNTRIES
NOS-M REPORT WITH CONCLUSIONS AND RECOMMENDATIONS FOR JOINT ACTIONS IN PERSONALISED MEDICINE IN THE NORDIC COUNTRIES
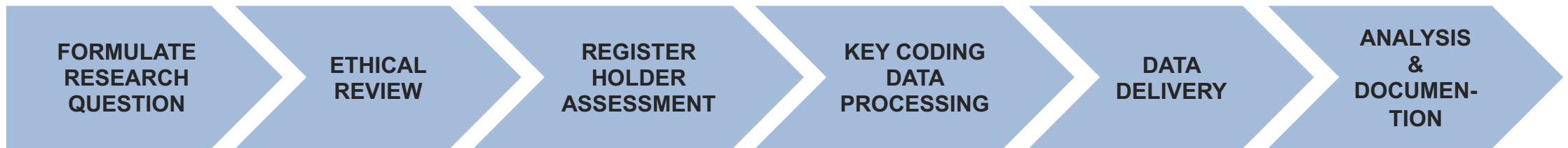
Health and Welfare:
a Nordic research priority

- NordForsk – Nordic institution that funds research and research infrastructure cooperation

- Major investments in health research (MEUR 50+) supported by all Nordic countries

- Focus on exploiting the Nordic strategic data resources – registers and biobanks – in research

- Data acquisition processes **are very time-consuming, includes many permits and issues of comparability**

Needs and potentials exceed system readiness

At present, Nordic collaborative projects are complex to manage and extremely time-consuming

FORMULATE RESEARCH QUESTION → ETHICAL REVIEW → REGISTER HOLDER ASSESSMENT → KEY CODING DATA PROCESSING → DATA DELIVERY → ANALYSIS & DOCUMEN-TION

➢ Limited knowledge of **what data exists**, where and its meaning – issues of comparability
➢ Limited knowledge of what **permits** are needed and what **procedures** are in place, even among researchers in the field
➢ Need to apply for **ethical permissions and data in each individual country**
➢ Data owners explicitly prohibit storage of data outside national institutions

Risks?

o Research not being performed or sub-optimally

o Nordic research losing a competetive edge

How to Reach the Nordic Potential?

- 2017-2019: Nordic effort to identify ways of improving secondary use of health data in research coordinated by NordForsk

- Supported by the Nordic Council of Ministers

- Task Forces on metadata, technology and legislation/ethics

- The idea of a Nordic Commons for health data presented

- Recommendations presented to Nordic policy level and Nordic Research Funders in 2020

A VISION OF A NORDIC SECURE DIGITAL INFRASTRUCTURE FOR HEALTH DATA: **THE NORDIC COMMONS**

NordForsk

https://www.nordforsk.org/publications

Vision for the Nordic Commons

"The Nordic region as a leading region for secondary use of health data"

This would require:

1. Nordic health data described with rich metadata according to the FAIR* criteria –**a federated Nordic Health Metadata Repository**

2. A Nordic **federated secure infrastructure** for processing sensitive personal data

3. A coherent **legal and ethical framework** supporting the above

4. A **funding programme** for technology and competence development (proof-of-value)
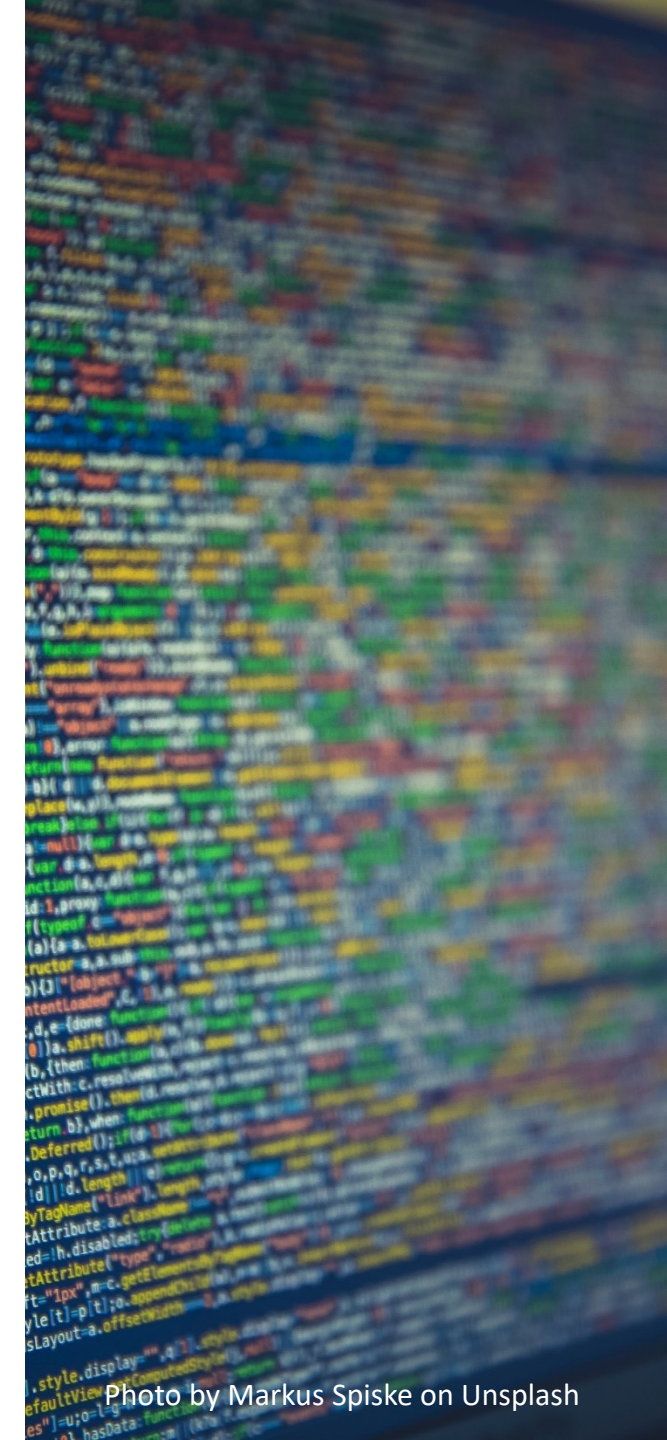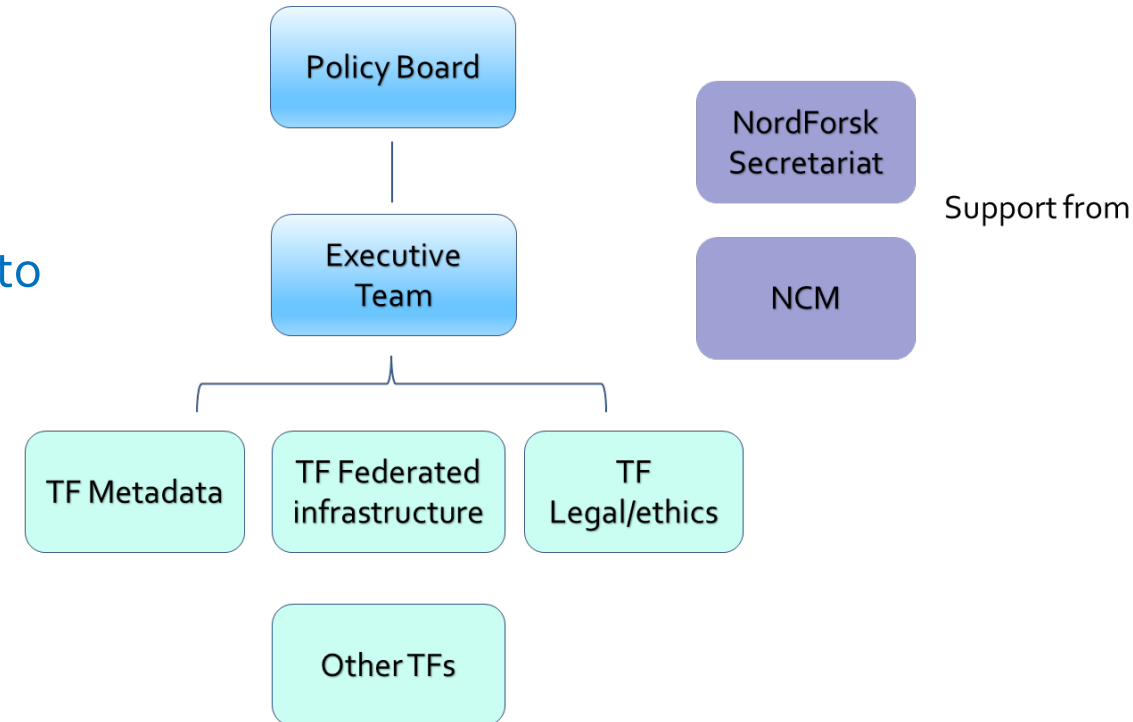
Findable, Accessible, Interoperable, Re-usable

Photo by Markus Spiske on Unsplash

The project has been kicked-off

- The Nordic Commons Project has been funded with appr. MEUR 3 (22 MDKK) between 2021-2024

- NordForsk tasked to provide administrative support to Policy Board and coordinating function

- Norway and Finland Lead countries

o **Focus of 2022:**
  o **engage and activate the Task Forces**
  o **identify and describe use-cases**

Policy Board

Executive Team

TF Metadata

TF Federated infrastructure

TF Legal/ethics

Other TFs

NordForsk Secretariat

Support from

NCM

Value beyond the Nordics

o   Activities under the Nordic Commons have great potential to also have impact on the international arena

o   Regional cooperation could develop proof-of-value for Europe (EHDS/ EOSC)

             - pilots or demonstrators based on Nordic health data

o   Essential to involve key national actors and to consolidate the work nationally

o   Nordic ecosystem could be used much more efficiently;

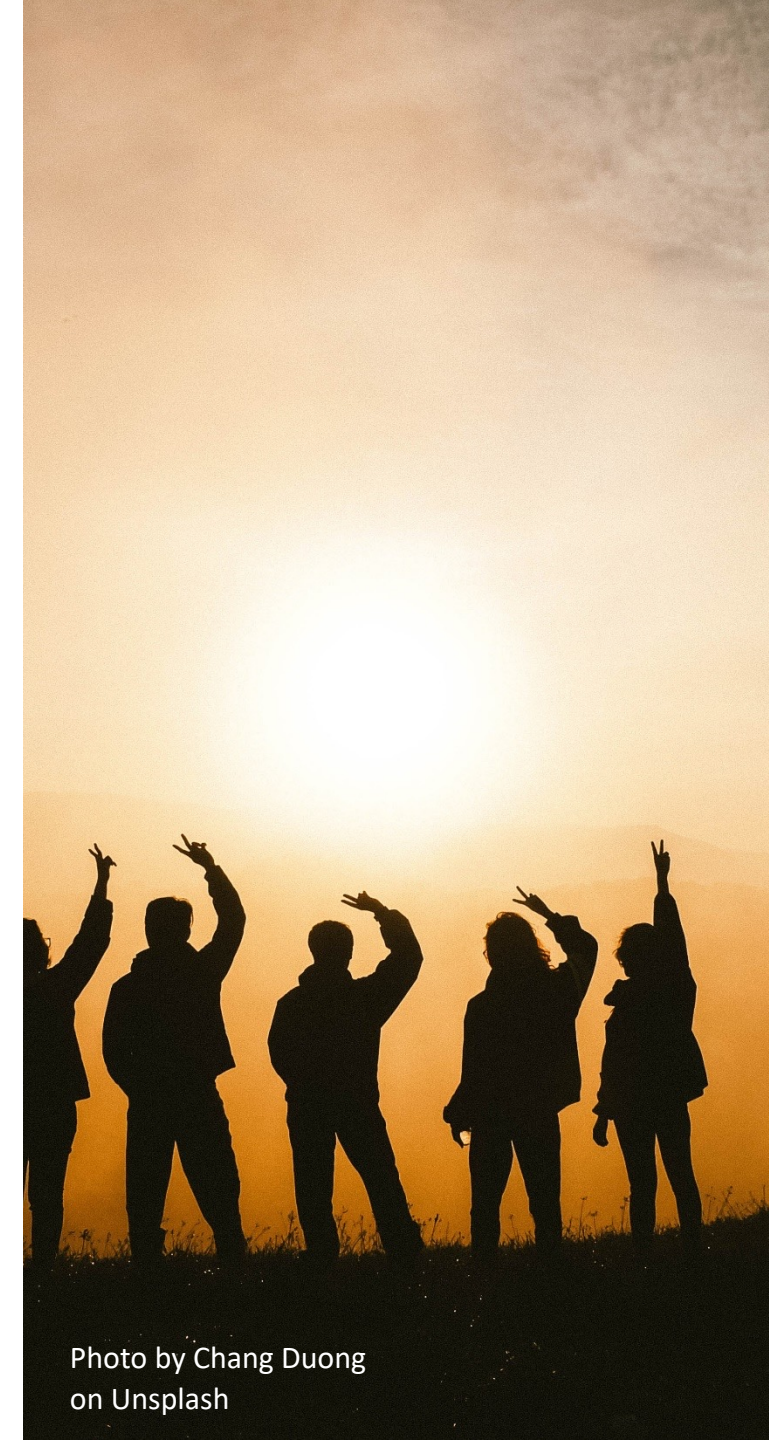o   **Unnecessary barriers need to be solved!**

Photo by Chang Duong on Unsplash

Thank you for your attention!

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