

CARE & FAIR principles: can both be embraced?

UNIVERSITY
of GUELPH

KASSY RAYMOND¹, AMARDEEP SINGH¹, NITIN SHARMA¹,
DEBORAH STACEY¹, THERESA BERNARDO²

(1) School of Computer Science, University of Guelph. (2) Department of Population Medicine, University of Guelph

GBADs

MOTIVATION

The **Global Burden of Animal Diseases (GBADs)** is a Gates Foundation-funded project with the goal to improve animal health by minimizing the economic and health burden of animal disease.

GBADs will act as a **data broker** for data artifacts - this includes the collection, assessment, curation, and dissemination of data resources through a Cloud platform, without owning the data. GBADs plans to do this through a **data portal**.

CHECK OUT OUR
PROTOTYPE DATA
PORTAL!

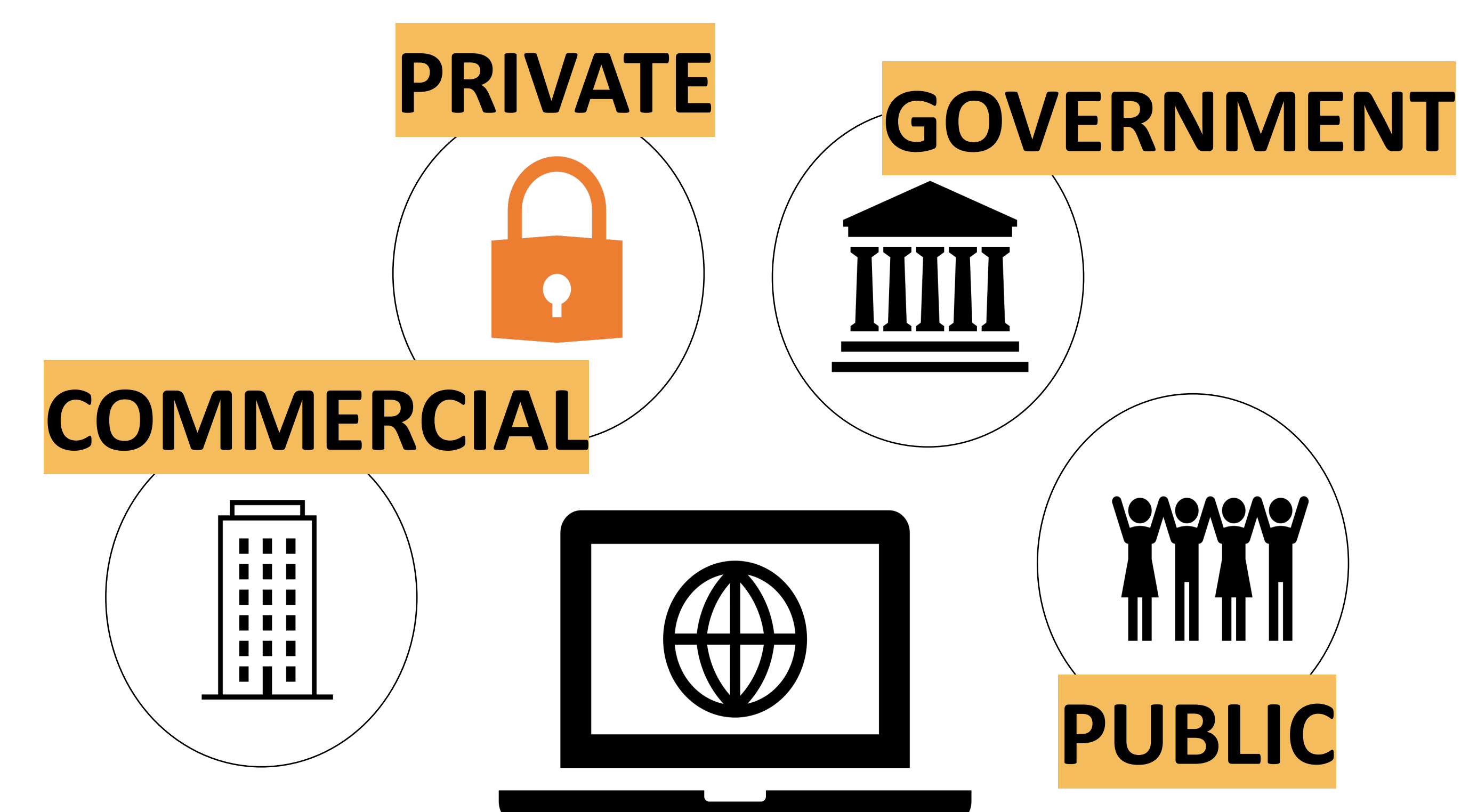
Link to our data portal:
<http://15.223.72.239:8050>

Collective benefit
Authority to control
Responsibility
Ethics

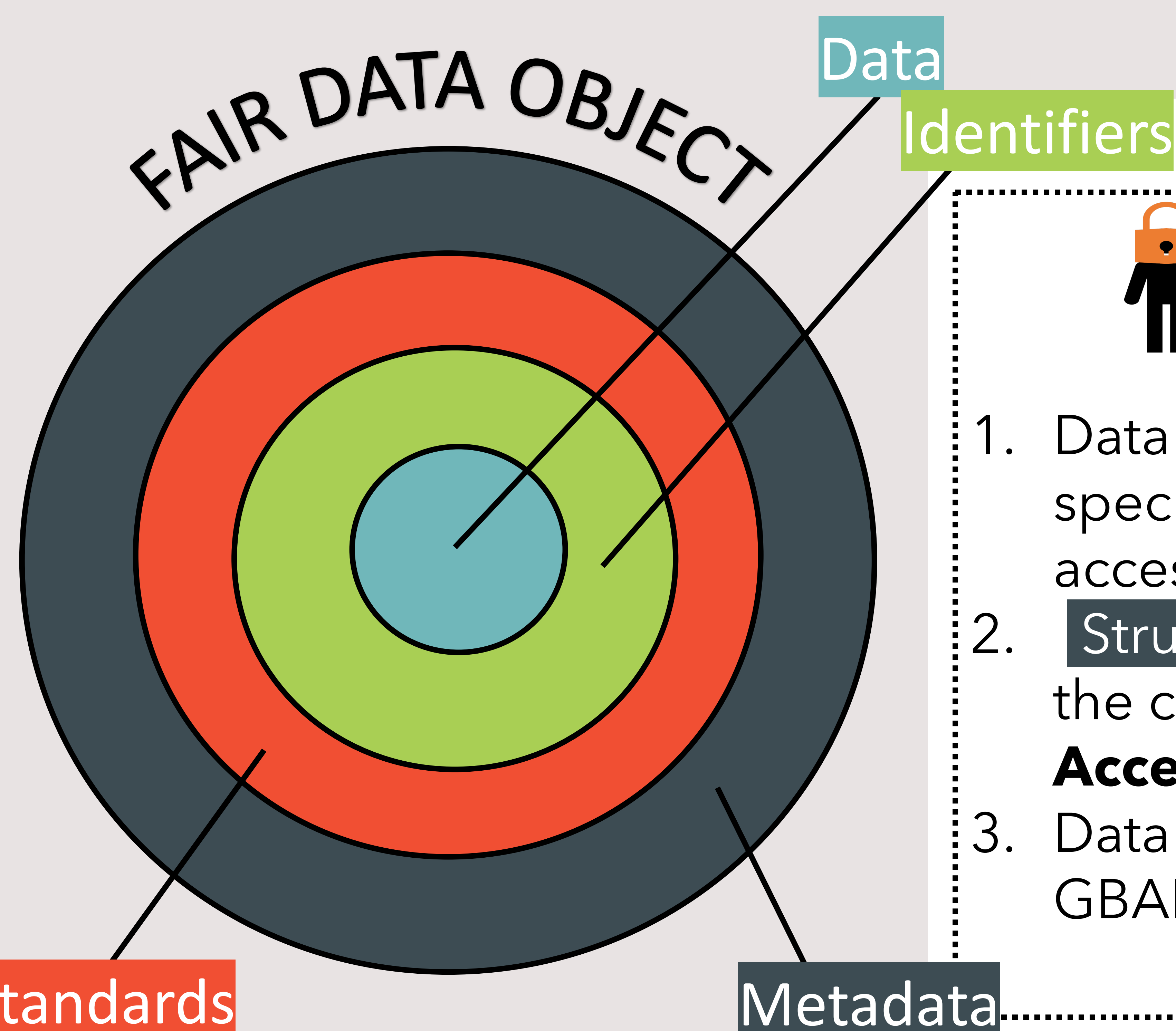
The global indigenous data initiative created the **CARE guiding principles** to articulate data sharing principles for indigenous data [1]. **These principles can be extended for the protection of private data stakeholders.**

INTRODUCTION

We anticipate 4 main types of data contributors. By identifying data contributors and users that are private, we can leverage the **Authority to Control** data.



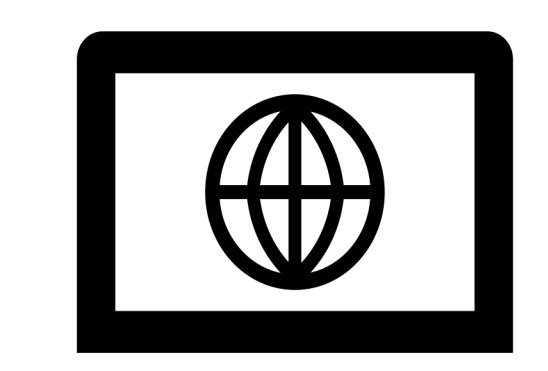


OUR APPROACH: DIFFERENT VIEWS FOR DIFFERENT CREWS



 **The private data contributor**

1. Data contributor only wants a specific user group to have access to data
2. **Structural metadata** reflects the choice of the data
3. Data is FAIRified within the GBADs system

Accessibility

-  Data that is 'open' can be seen by all data users
-  Private data locked by default
- User creates profile → user type selected → user type verified
-  User **granted unique view of data** based on privacy specifications in structural metadata of data objects

CHALLENGES

1. Identification of data user types.
2. Verification of user types.
3. Lack of policies/guidelines for publishing models that use private data.

References:

- [1] Research Data Alliance International Indigenous Data Sovereignty Interest Group. (September 2019). "CARE Principles for Indigenous Data Governance." The Global Indigenous Data Alliance. GIDA-global.org
- [2] Hodson, Jones et al. (2018) Turning FAIR data into reality. Interim report of the European Commission Expert Group on FAIR data. <https://doi.org/10.5281/zenodo.1285272>