STANDING Together
STANdards for Data Diversity, Inclusivity and Generalisability

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BACKGROUND

> **MISSING DATA MATTERS:** it can **exacerbate inequalities** on a **societal scale**. When that data is operationalised into algorithmic decision-making systems and AI, the **social processes that produce racial inequality**—mechanisms of **power, economics, knowledge, culture and language**—can be written into technologies with **huge societal impacts.**
>
> *- Ada Lovelace Institute*

In the coming decade, machine learning algorithms and other AI systems (hereafter AI/ML) trained using healthcare data will transform many aspects of healthcare, equalling or surpassing expert clinical performance whilst reducing harmful variations in care. **(1,2)** Whilst AI/ML can widen access to personalised healthcare, it can also reflect or even amplify existing societal biases. **(3,4)**

Healthcare provision is already systematically poorer for minoritised groups in society, generating underserved subpopulations for whom healthcare is harder to access, poorer in 'quality', or both. (5) When minoritised people are excluded from healthcare, they cannot contribute to health datasets, which are commonly derived from routinely collected real-world healthcare data. Additionally, record completeness, incorrect or oversimplified demographic information, and inconsistent terminology can compromise health data quality, and these factors may not be uniform across demographic subgroups. Large international eye imaging and skin cancer datasets – key targets for AI development - demonstrate that demographic information is often absent, and when present demonstrates poor generalisability to real-world populations. **(6,7)**
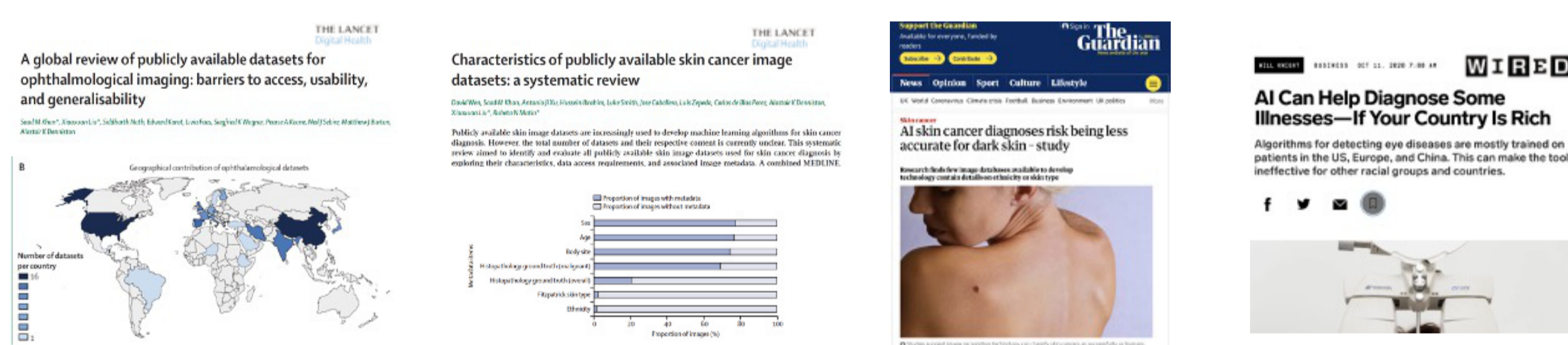
The resulting **"health data poverty"** prevents those who are poorly represented in health datasets benefiting from future AI/ML innovations. (8) Biases in training and test datasets are an important source of algorithmic bias which contribute to variable performance of AI/ML for traditionally underserved populations, compounding existing health inequalities. **(9,10)**

AIM

STANDING Together will work with members of the public and international stakeholders to develop standards for health data to support development of AI/ML tools which do not disadvantage minoritised population groups.

We hope that this work sparks a transition to transparency, diversity and generalisability in health datasets, leading to fair and equitable AI for all.

METHODS

STANDING Together will deliver a number of work packages which together will create consensus-derived standards for governing health datasets, and investigate potential barriers to their adoption.

1: A literature search will identify existing practice in healthcare AI/ML development, which will be condensed into key themes to the inform the Delphi study. Members of the public, medical device regulators, AI/ML developers, clinicians and other key stakeholders will be invited to participate in a two round e-Delphi study followed by a consensus meeting, which will translate these themes into a work able set of dataset standards.

2: Systematic reviews will be conducted to discover health datasets relating to heart failure, COVID-19, and breast cancer - all of which are recognised to disproportionately impact minoritised groups. **(5,11,12)** Demographic composition of these datasets will be summarised and compared across disease areas, highlighting reporting methods, data missingness & variations in quality. The e-Delphi-derived standards will be applied to these datasets to identify gaps between existing practice & these new standards.

3: Finally, curators of health datasets will be invited to participate in structured interviews, exploring barriers to data inclusivity & diversity, and how these might be addressed.

PATIENT & PUBLIC INVOLVEMENT

We are a diverse team, but we don't fully represent the whole wider population. We've recruited a patient and **public involvement and engagement subcommittee** who help us with moral and ethical issues, contributing their lived experience to make sure our standards meet the needs of wider society
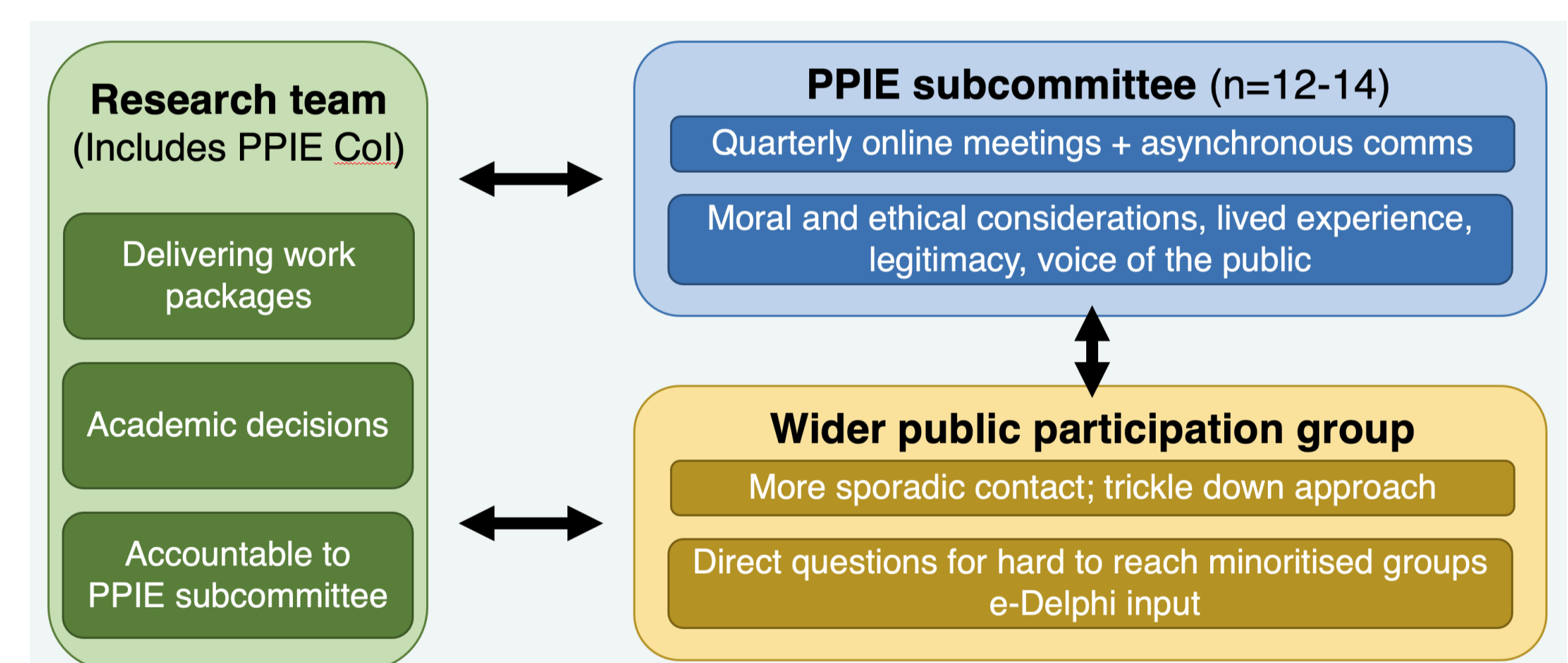
OUTPUTS & POTENTIAL IMPACT

STANDING Together's international group of investigators include medical device regulators, clinicians, computer scientists, ethicists, and patient & public representatives.

Standards produced by this project will likely be adopted internationally by medical regulators, and will constitute 'best practice' in health dataset curation.

JOIN OUR E-DELPHI STUDY
And help us make sure these standards work for you:

www.datadiversity.org/delphi
Register interest at above link; study starts Sept 2022