

Research funding and priority setting

#EDIS2019

35%
of R&D funding goes to
London and the South East.

– Academy of Medical Sciences, The British Academy,
The Royal Society and the Royal Academy of Engineering
“Investing in UK R&D”
Report (2019)

Research funding and priorities are often
mismatched with the community’s desires
and needs.

– Liz Pellicano, Adam Dinsmore and Tony Charman
“A Future Made Together: Shaping autism research
in the UK” (2013).

No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.

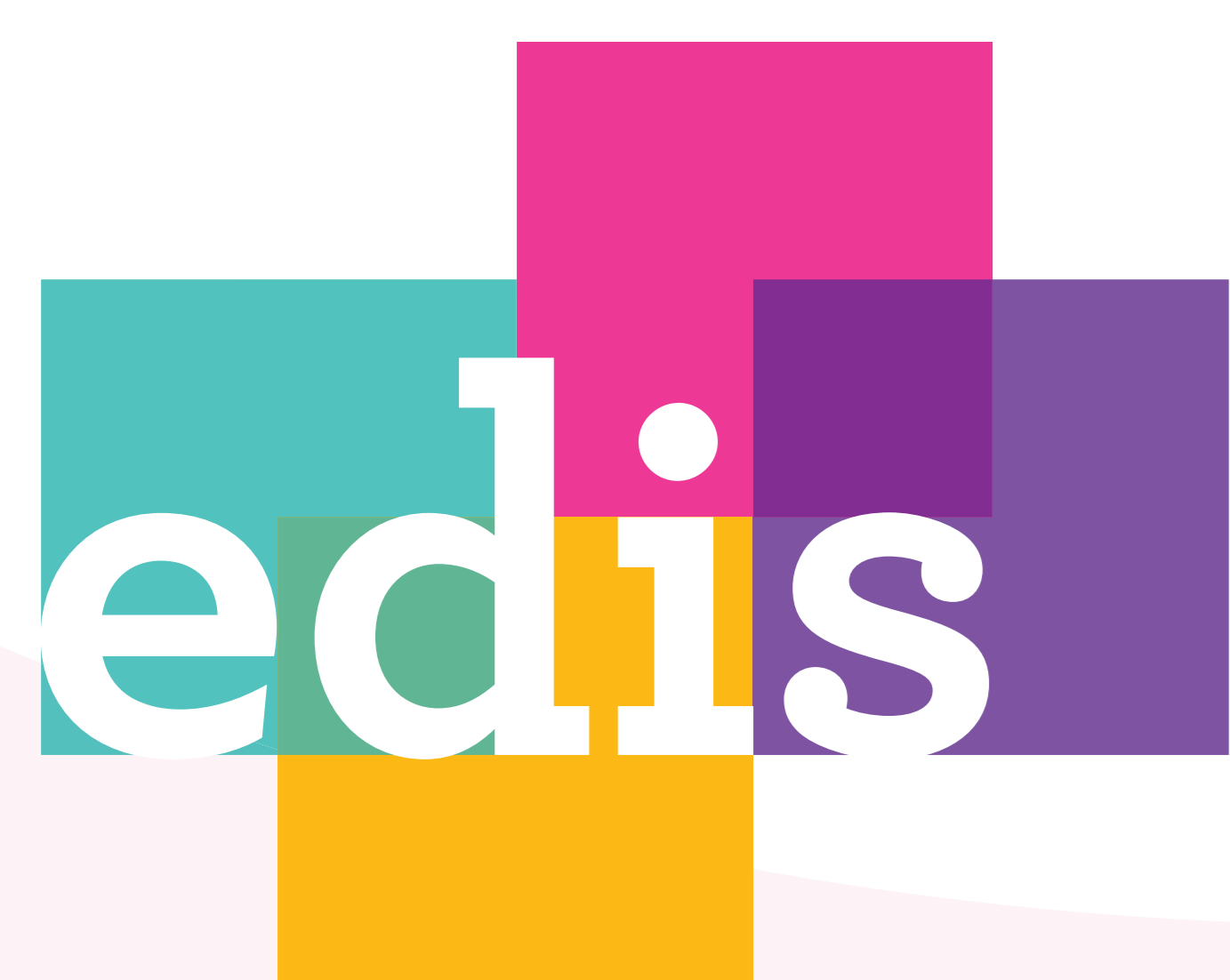
– Dame Sally Davies
“Exploring impact: public involvement in NHS,
public health and social care research” (2009)

Currently, we are concentrating the research we do in the parts of the country that are the healthiest, rather than the sickest. It isn’t difficult to imagine that this might skew research priorities.

– Richard Jones and James Wilsdon
“The Biomedical Bubble”
Nesta (2018)

Key questions for this session...

1. What are the challenges for this topic?
2. What have you been doing in this area?
3. What should the future of this theme look like?



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The sex and gender dimension in research

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For biomedical research, sex-related reporting in publications was just 31% in 2016, less than half compared to in clinical medicine (67%) and public health research (69%).

– Cassidy Sugimoto, et al

“Factors affecting sex-related reporting in medical research: a cross-disciplinary bibliometric analysis”

The Lancet (2019)

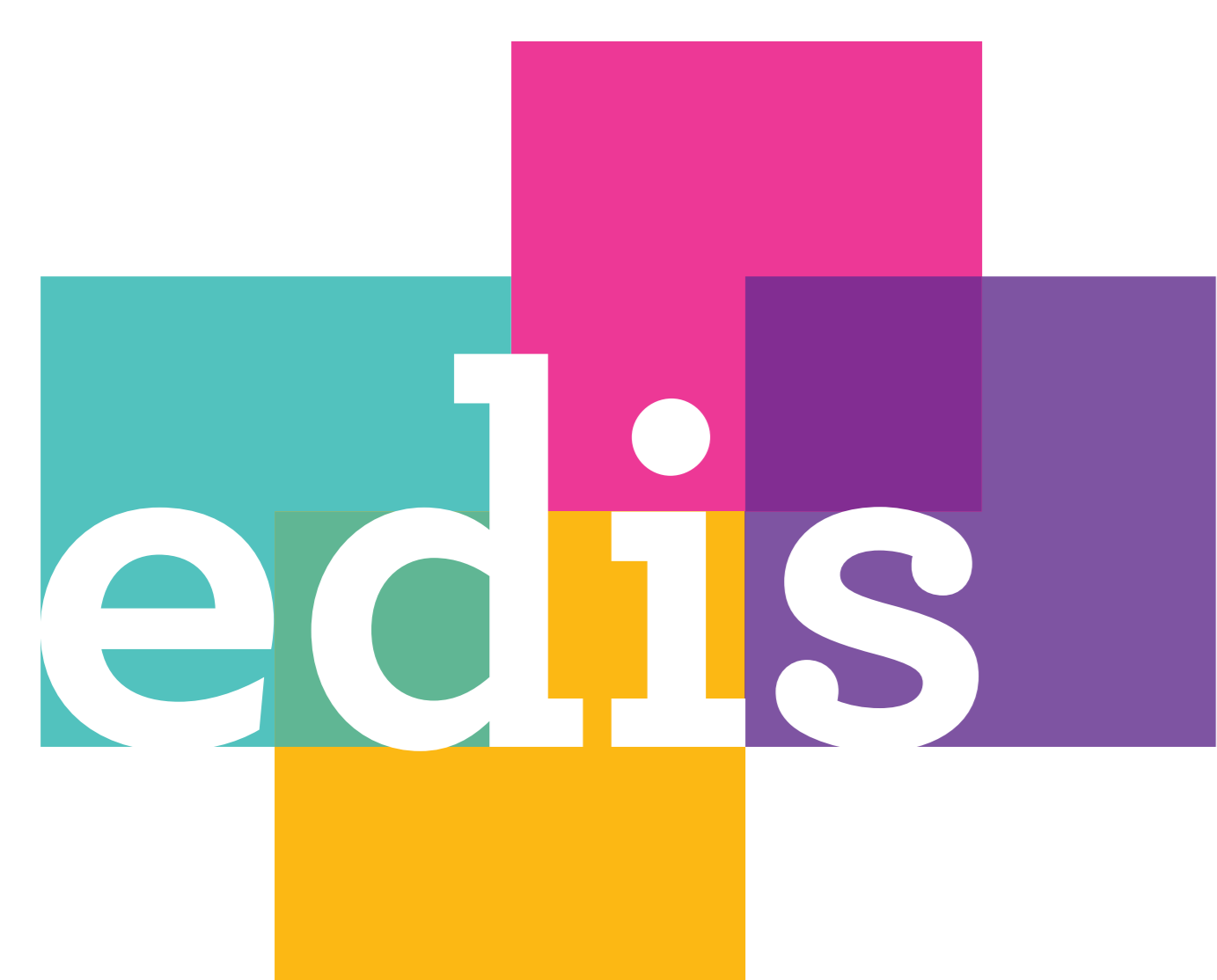
Gender identity and stereotypical gender roles in society have a significant impact on health outcomes and healthcare experiences.

– World Health Organisation

“Gender, equity and human rights: Gender”

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Ethnicity and ancestry in genomics

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80% of individuals included in GWAS studies **are of Western European descent**

– Alice Popejoy and Stephanie Fullerton

“Genomics is failing on diversity”
Nature News (2016)

Social determinants of health are often far more important than genetic determinants of health, but that doesn't mean genetic determinants aren't important.

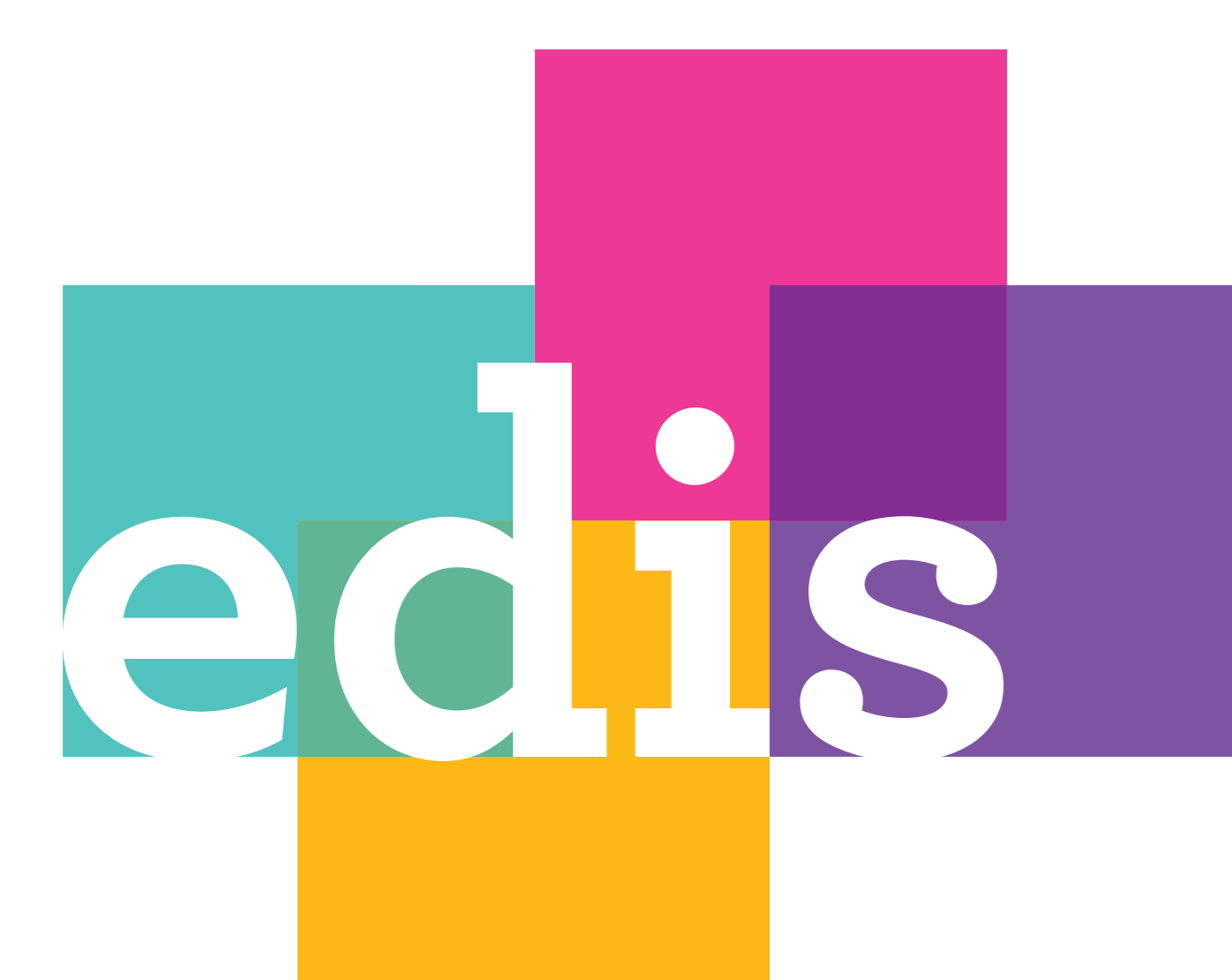
– Carlos Bustamante



Imprecise use of race and ethnicity data as population descriptors in genomics research has the potential to miscommunicate the complex relationships among an individual's social identity, ancestry, socio-economic status, and health, while also perpetuating misguided notions that discrete genetic groups exist

– Vence Bonham, Eric Green, Eliseo Pérez-Stable

“Examining How Race, Ethnicity, and Ancestry Data Are Used In Biomedical Research”
Jama (2018)



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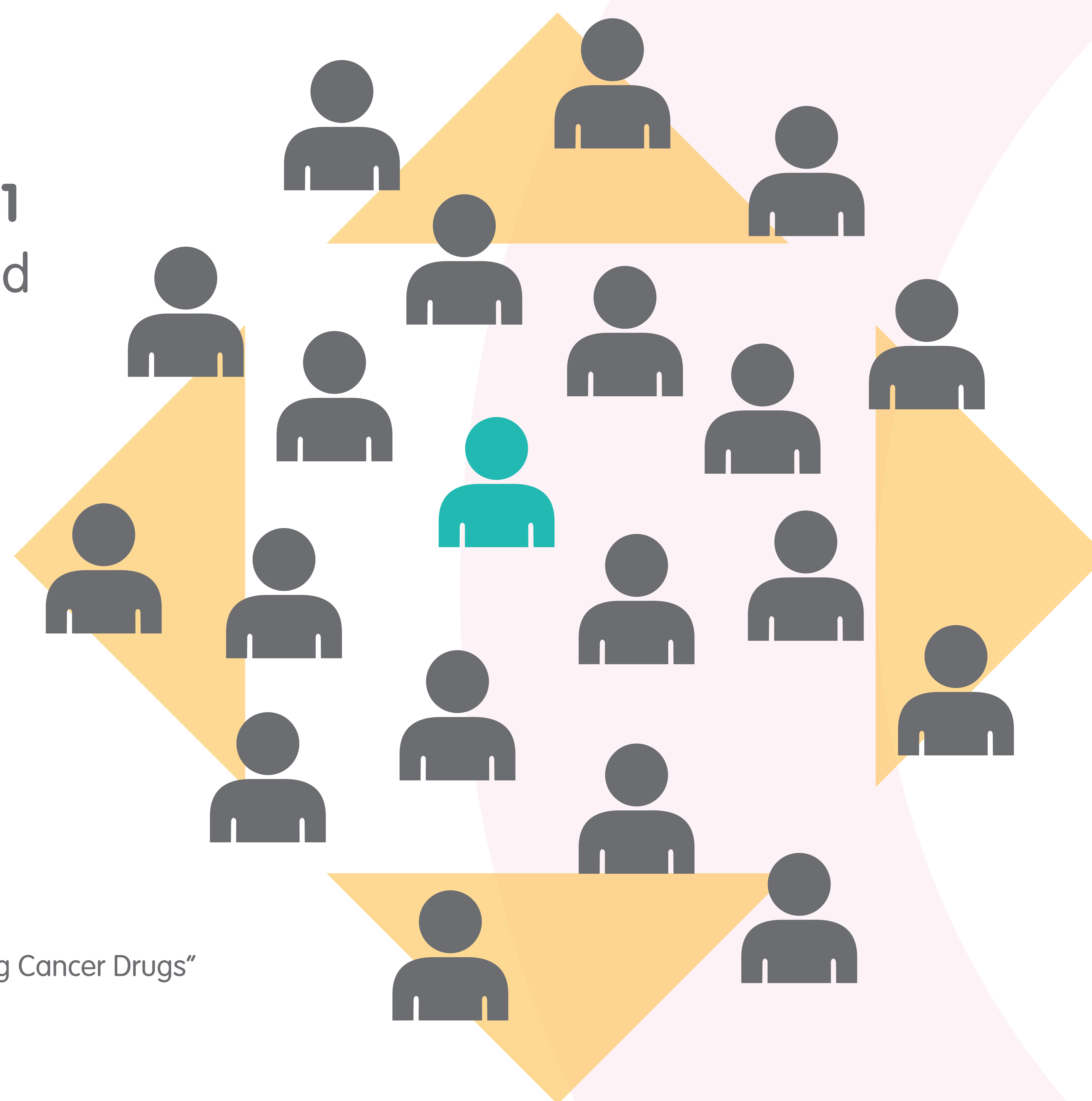
Diversity in clinical trials

In trials for **24** of the **31** cancer drugs approved in the US since 2015, **fewer than**

5%

of the patients were Black or African American.

– **Caroline Chen and Riley Wong**
“Black Patients Miss Out On Promising Cancer Drugs”
Propublica (2018)



Women are generally underrepresented in phase I clinical trials

– **Geert Labots, et al**
“Gender differences in clinical registration trials: is there a real problem?”
British Journal of Clinical Pharmacology (2018)

People with disabilities are largely absent from research not directly linked to their disability, often due to exclusion criteria.

– **Maurice Feldman et al**
“Inclusion of children with disabilities in mainstream child development research”
Disability & Society (2013)

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BAME participation in health research

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The use of language, ability to speak English, availability of translation and interpretation can be a large barrier to many communities' ability to be involved in health research.

Working with members of the public in research operates in a context of imbalanced power relationships between people, researchers and institutions. Even more so if your aim is to work with those who may be considered as vulnerable, discriminated against, marginalised or lacking power.

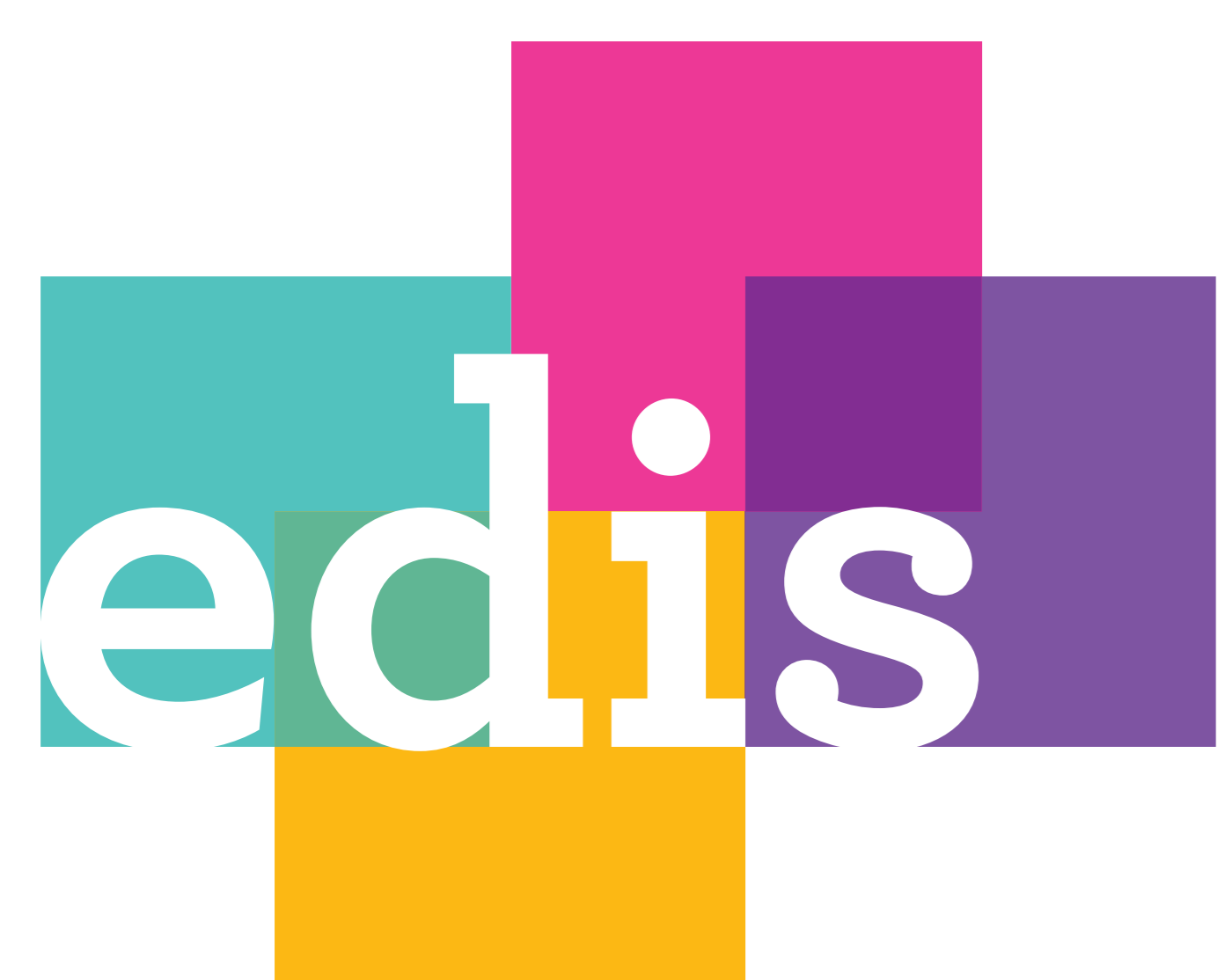
- **Being Inclusive in Public Involvement (PI) in Health Research**
Guidance published by NIHR INVOLVE

"White men in white coats... why should I help them?"

- **Patient insight**
Wellcome Trust's BAME inclusion in mental health project

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Involved research communications



All voices should be heard, not just the loudest or most confident and articulate.

– Cassie Wilson

People from ethnic minority and lower socioeconomic groups feel far less confident about being treated with dignity and respect in research compared to their White and higher socioeconomic counterparts (35% of ethnic minority respondents feel confident compared to 50% of White respondents)

– Amanda Hunn

“Survey of the general public: attitudes towards health research”
Health Research Authority (2013)

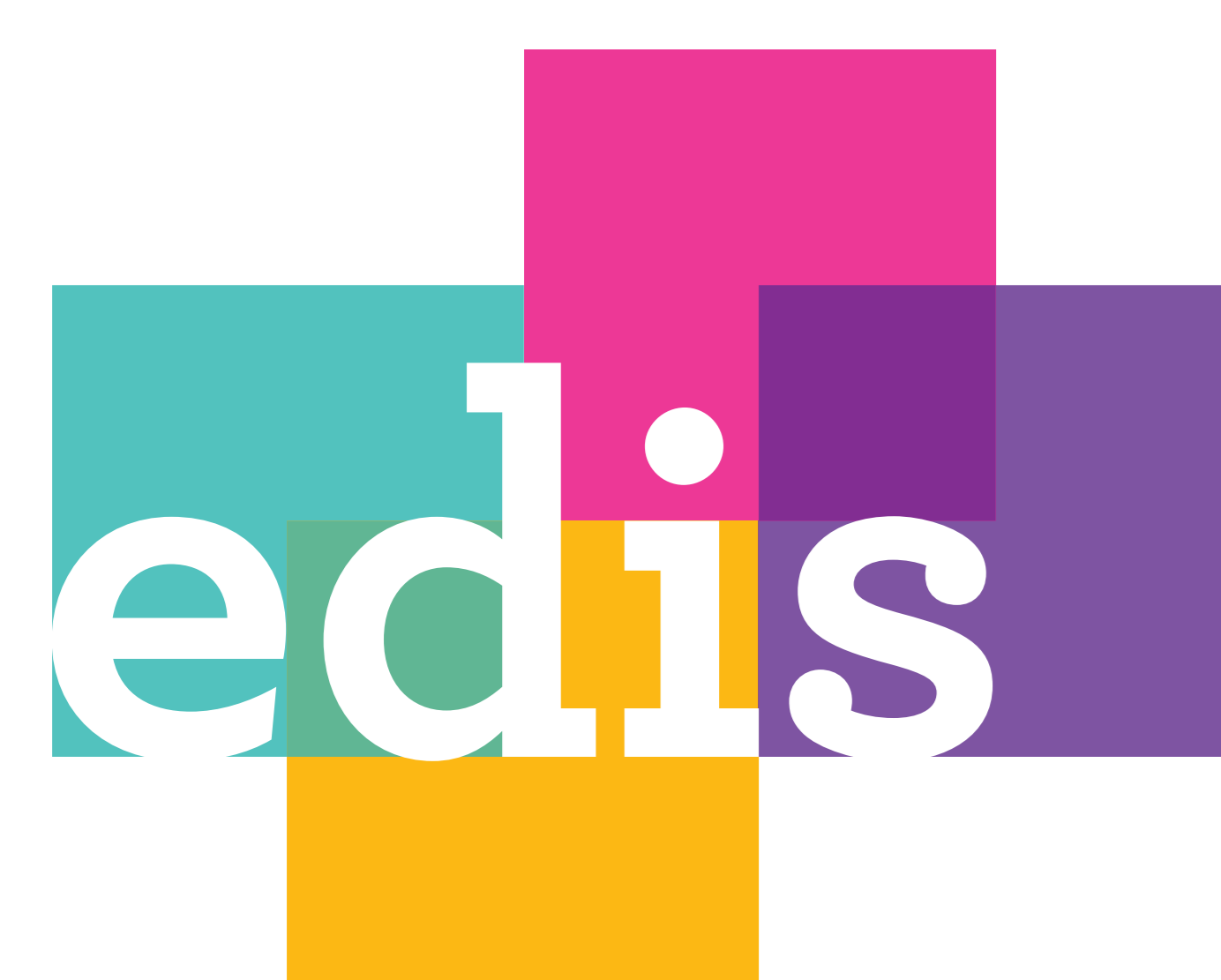
A diverse and inclusive public involvement community is essential if research is relevant to population needs and provides better health outcomes for all

– NIHR

“Going the Extra Mile”
Report

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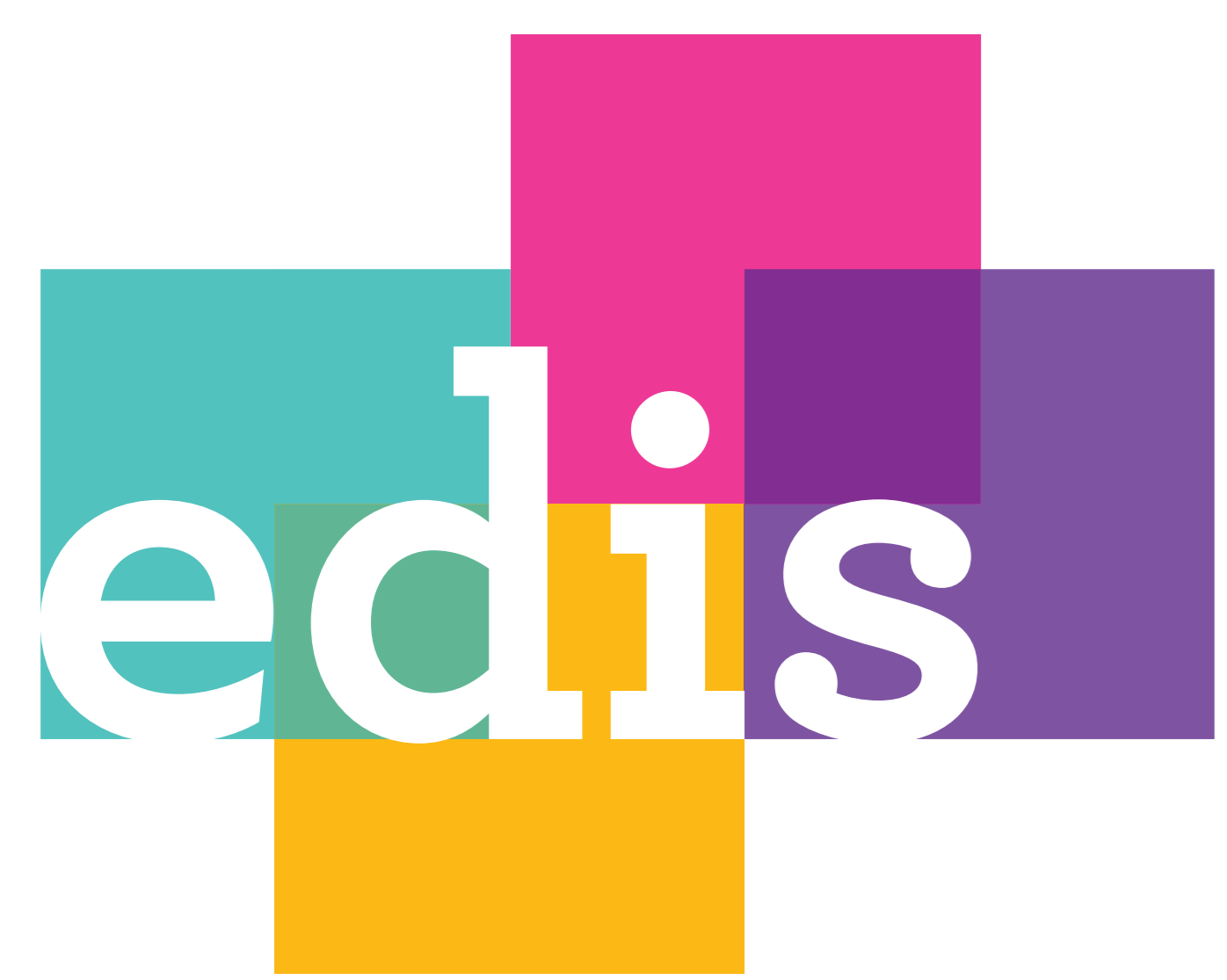
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What topics should EDIS explore next ?

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