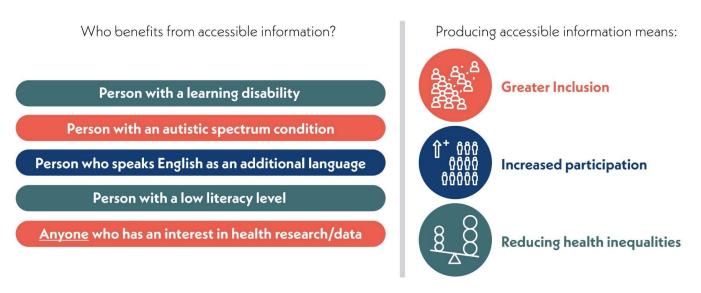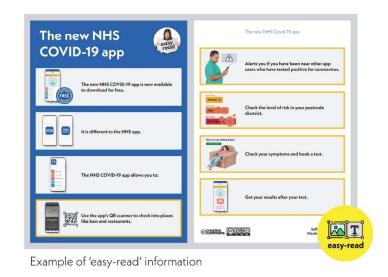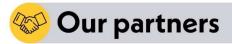# Large data sets & Accessible Information

🏆 Our aim

To create digital materials, based on easy-read design principles, to increase understanding of data set usage in health research in those communities where usual information is more difficult to understand.

We will primarily be aiming our materials at people with an additional communication need, but also hold the expectation that accessible materials support anyone who is new to research, patient data, or health studies.

Who benefits from accessible information?

- Person with a learning disability
- Person with an autistic spectrum condition
- Person who speaks English as an additional language
- Person with a low literacy level
- Anyone who has an interest in health research/data

Producing accessible information means:

- Greater Inclusion
- Increased participation
- Reducing health inequalities

Example of 'easy-read' information

🤝 Our partners

NIHR | National Institute for Health Research

NIHR funded large data set research studies:

1. PERMIT concerns improving understanding of secondary medication use in Type 2 Diabetes.
2. ESORT concerns improving understanding of clinical decision making in emergency surgery for common acute conditions.

Understanding Patient Data

Understanding Patient Data aims to make uses of patient data more visible, understandable and trustworthy, for patients, the public and health professionals.

We work with patient groups, charities, NHS organisations and policymakers.

Centre for BME Health
reducing health inequalities

The Centre for Black and Minority Ethnic (BME) Health has one clear vision:

"To reduce ethnic health inequalities". We do this by working with patients, the public, community and voluntary sectors, researchers, health and social care organisations.

PROVISIONAL

⚙️ Co-production

We will create a co-production group, consisting of:

Adults with learning disabilities and / or autism as well as family carers with experience of engagement in health service delivery.

NIHR | National Institute for Health Research

NIHR Patient Research Champion with experience of large data set research use.

Graphic designer with experience of creating health and community care accessible information, including recent NIHR clinical trials material.

NHS/NIHR research delivery practitioner

Co-production Group Action

Engage group understanding of health research using easy-read video and graphic material recently developed for Understanding Clinical Trials

Review Understanding Patient Data current material as a resource to develop and to avoid duplication

Identify and create core information for general accessible information led understanding of research using large data sets

Engage group understanding of specific PERMIT and ESORT data studies

Create accessible information led understanding of the PERMIT and ESORT data studies. This is especially important regarding the PERMIT study as recent data indicates the prevalence of diabetes in people with a learning disability is nearly double the rate of the general population.

Project outputs

Easy-read digital booklets / leaflets

Animation (in an easy-read 'Talking Text' format)

Videos as personal stories

Materials which are culturally and linguistically appropriate in respect of different ethnicities (provisional)

PROVISIONAL