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‘Designed with, not for’

Patient and public involvement in accessible health information for people with intellectual disabilities: the TRANSFORM prostate cancer screening trial

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Where opportunity creates success

People with intellectual disability and cancer screening



People with an **intellectual disability** may find it hard to get the health help they need.



They might be at a **higher risk** of some cancers, like prostate cancer.



But they often get **screened less** than other people. This means they might not get the tests they need.



They might rely on **carers** or supporters to help them go to health checks.



This can happen because the **information** about screening can be hard to understand.

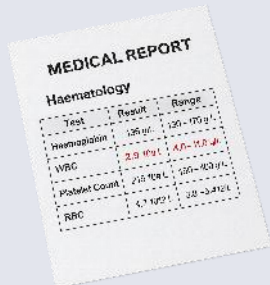
The TRANSFORM trial



The **TRANSFORM trial** is a big study in England about prostate cancer screening.

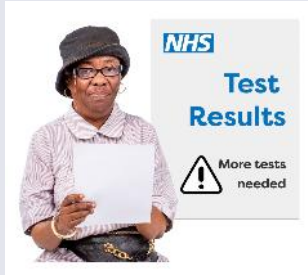


The trial wants to see if we can **find cancer early** using different tests.



These tests include the **PSA blood test, MRI scans**, and something called **polygenic risk scores**.

Why is this trial important?



The UK does not have a national programme for prostate cancer screening yet.



The **TRANSFORM trial** is trying to find out if there should be one.



Everyone should have the **information** they need to make choices about their health.



This includes people with **intellectual disabilities**.



Involving the **public** and patients can help make health trials more accessible.



People should help **design** information, not just receive it.

What we did



There were several **focus groups** to talk about health and the trial.



People with intellectual disabilities and their families **helped redesign** the trial materials.



They gave **feedback** on what worked and what didn't.

What we found



Six main **themes** were found from what people said.

1 · Making information understandable



One theme was about making **information understandable**.



Words like **PSA** and **MRI** need to be explained clearly.



Using **plain English** and words like 'you' can help make information clearer.

2 · More than easy read



Easy read materials aren't always enough on their own.

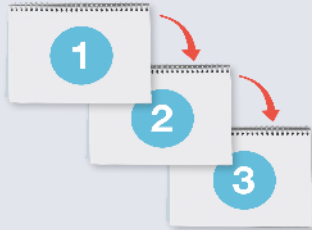


Some people might need **audio**, **video**, or animations to understand better.

A clear patient journey



It's important to show what will **happen** at each health visit.



This helps people know what to **expect**.

3 · Randomisation explained



The trial also needs to explain
randomisation in a better way.

3 · Communicating risk



It was important to say a **high PSA** does not always mean cancer.



Good **communication** is key, and people should feel comfortable asking questions.

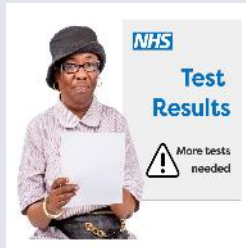
4 & 5 · Adjustments, and getting results right



We discussed ideas of **reasonable adjustments** for people.



This includes things like seeing the space first or having a **longer appointment**.



Getting **results** in a way that works for each person is also important.

6 · Equity, culture and trust



Trust is important, especially for some **minority communities**.

Recommendations made



We made several **recommendations** for the materials used.

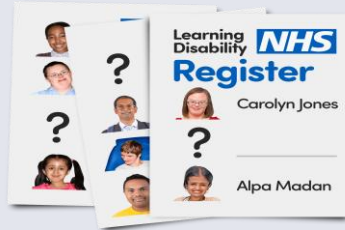


These included the need for information in multiple formats. For example, **animations**, an FAQ booklet, and other formats.

Why it matters



We wanted to make sure the materials were a clear **redesign** and not just a consultation.



It showed that people with intellectual disabilities can be part of trials with the right support.



Understanding leads to **genuine consent** and autonomy.



If trials don't include people with intellectual disabilities, the **evidence** won't be fair for everyone.



“Nothing
about us,
without us”



PROSTATE CANCER UK

TRANSFORM



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Thank you

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