

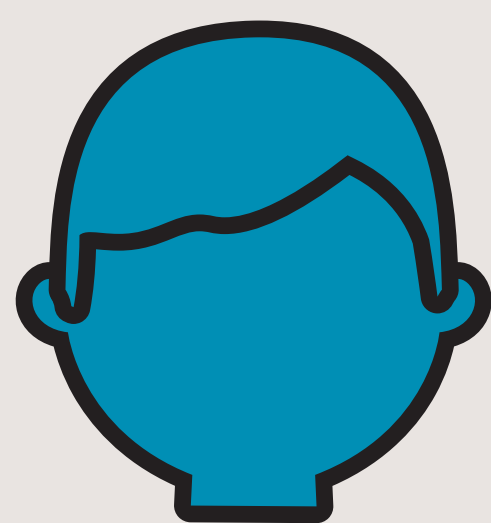
# Standardising FASD diagnosis



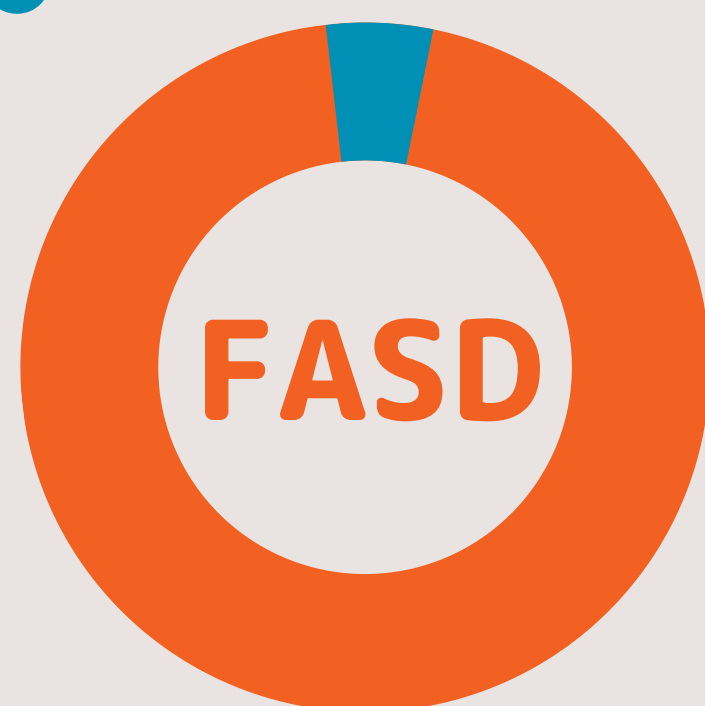
In this session, Prof Raja Mukherjee and Dr Neil Aiton talked about how FASD diagnosis has changed over the years.



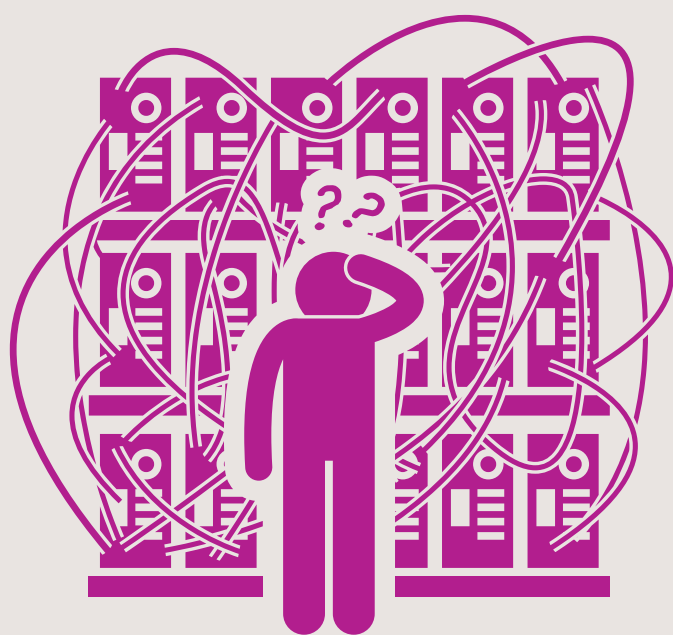
The first diagnosis was in 1973, nearly 50 years ago.



Back then doctors diagnosed someone if they had certain facial features. This used to be called Fetal Alcohol Syndrome.



But then they learnt that only a tiny number (about 2-5%) of those with FASD have those facial features. They learnt the facial features don't matter so much.



## FASD is brain-based

As years went by they began to look for other ways to tell if someone was affected by alcohol exposure in pregnancy.

From the early 2000s they started to look for ways to test how someone's brain is working.

So they tested things like - how does someone take in new information?

How is their memory?

What are the other ways they are affected?

Different experts came up with different ways to diagnose FASD. It got complicated. They were using 256 codes and lots of different terms at one point!



Old terms  
FAS  
pFAS  
ARND  
ARBD  
PAE

New term

FASD



+  
+  
+  
+  
428!  
+

## Simplifying diagnosis

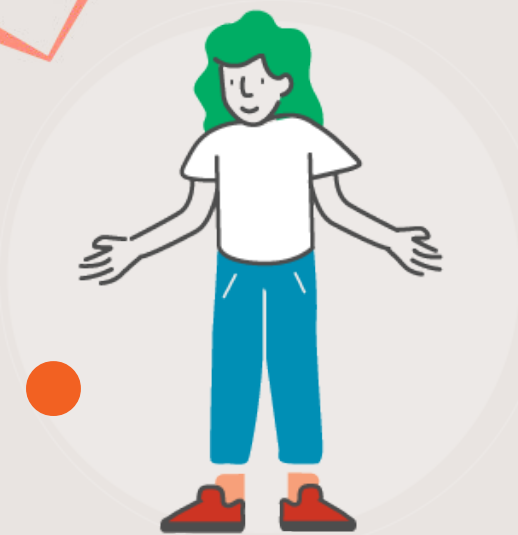
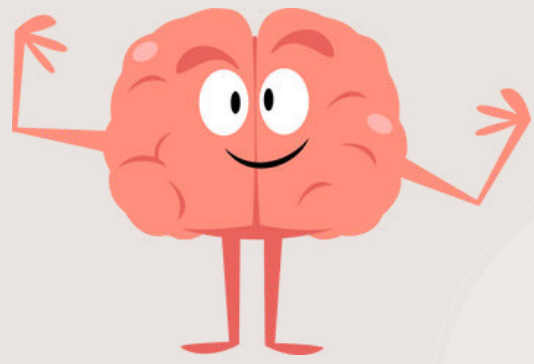
Canada came up with a simpler system that Scotland used to make their SIGN guidelines. These SIGN guidelines are also now used England and Wales too.

Today the UK uses the term 'FASD' as a diagnosis.

International experts are still working to try to improve FASD diagnosis.

But they all agree strongly that alcohol can cause harm to a baby in the womb and that it's important to diagnose FASD.

Diagnosing FASD is complicated because there are more than 400 conditions that can co-occur and each person is affected differently.



**NICE** National Institute for  
Health and Care Excellence



## So what?

People ask all the time what is the point of making an FASD diagnosis?

Experts agree It's important to understand the way the brain and body were affected by alcohol in the womb to be able to best help the person.

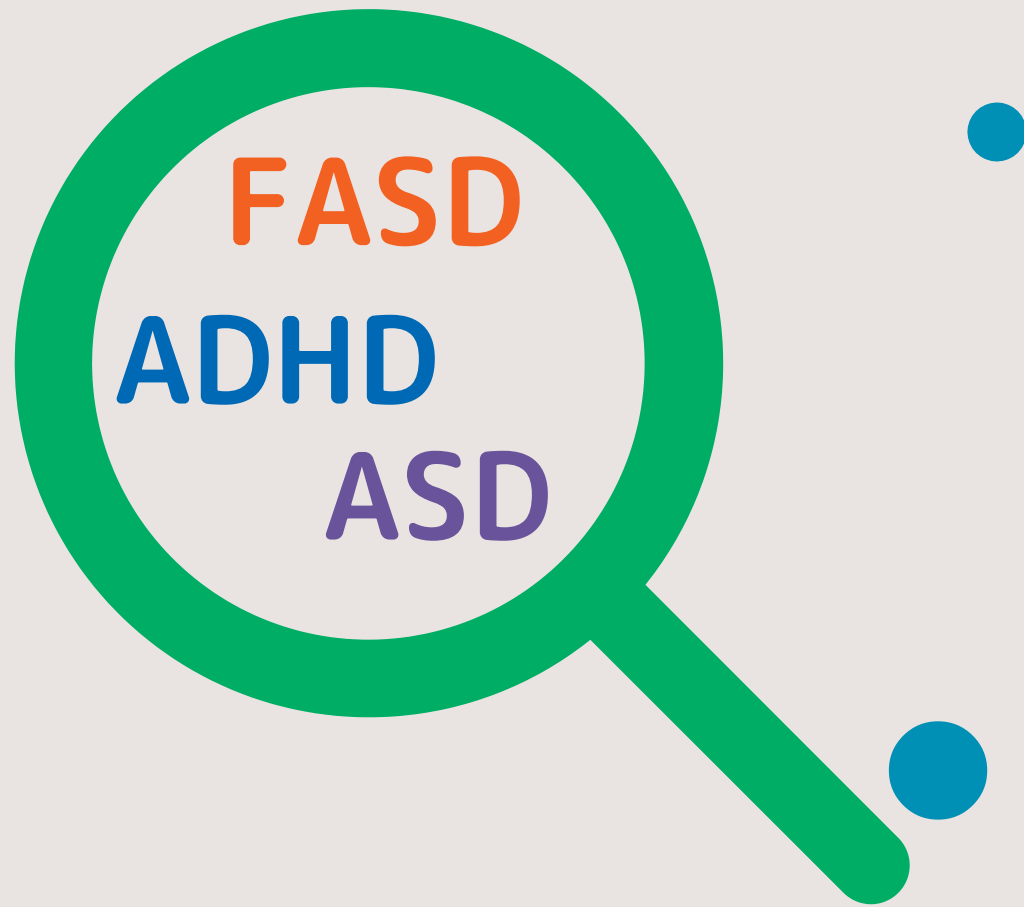
This is especially important as a new NICE Quality Standard on FASD calls for a care plan for people with FASD.

To have a proper care plan, you first have to understand how each person is affected , what their strengths are, as well as things they need help with.

This needs input from a team of different experts, because FASD is complex.

## Other things to consider

When diagnosing, it's important to know the relationship between FASD and other conditions like ADHD and ASD because it will change how they are managed.



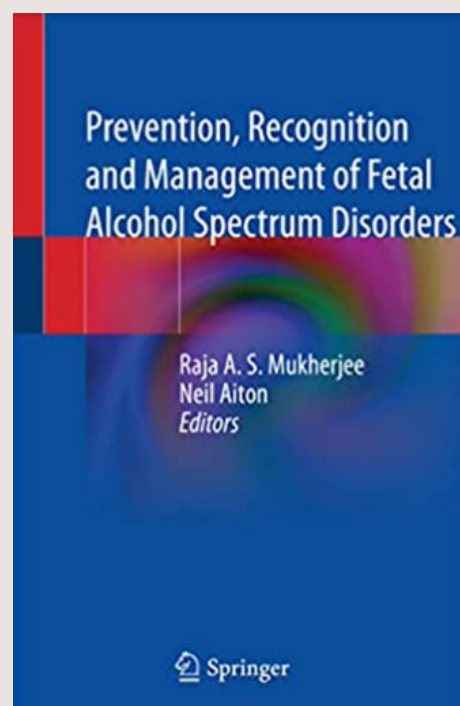
Most of the tests to see how someone's brain works can only be done when the child is old enough to answer questions. What about babies and toddlers? Experts are looking for a way to diagnose them sooner.



Experts also say people with FASD should be re-assessed and supported throughout their lives. Diagnosis isn't the end of the story, it's the beginning.



## What is Raja and Neil's FASD Book Club?



Prof Raja Mukherjee and Dr Neil Aiton wrote a book for other doctors about FASD. But they hope more people can access the information.



In this online book club people who wrote chapters give 15-minute talks about what they wrote and then they answer questions.



After each book club, the talks are shared on National FASD's YouTube channel.



You don't have to read the book. It's expensive because it's for libraries and universities. But if you want to order it, it's here:

<https://tinyurl.com/RajaAndNeilFASDBook>