FASD Coding for Primary Care

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University of BRISTOL

NIHR | School for Public Health Research

Meet the team

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Outline

- FASD
- Why ask & advise about alcohol in pregnancy?
- NICE Guidance, Diagnostic Terms & Coding
- Advise & Ask
- Code
- Share
- Knowledge Mobilisation

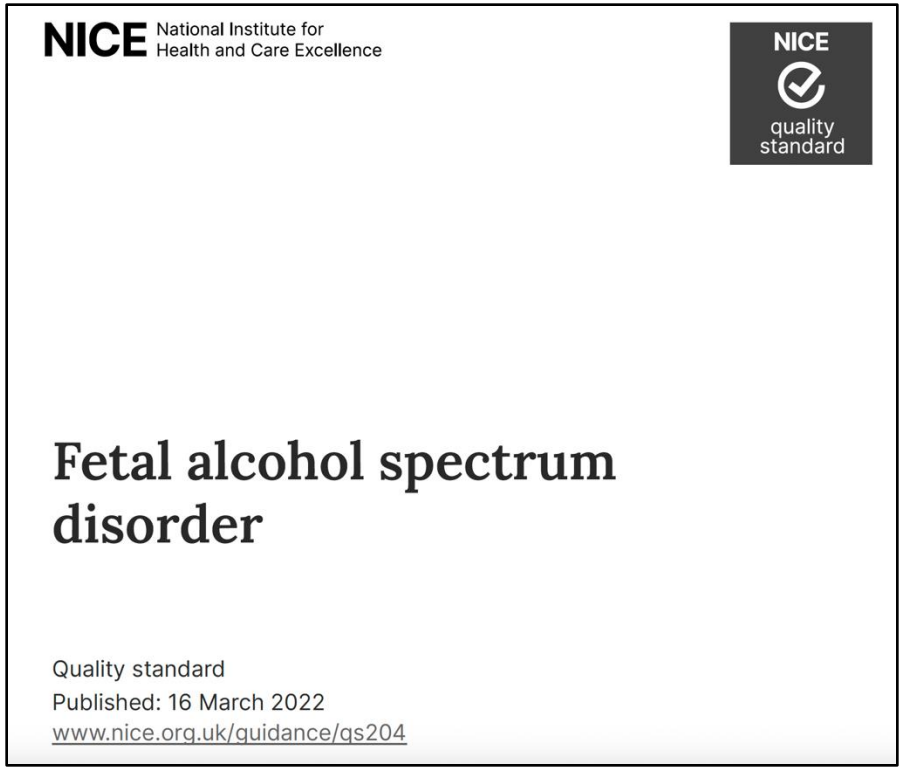
FASD – the basics

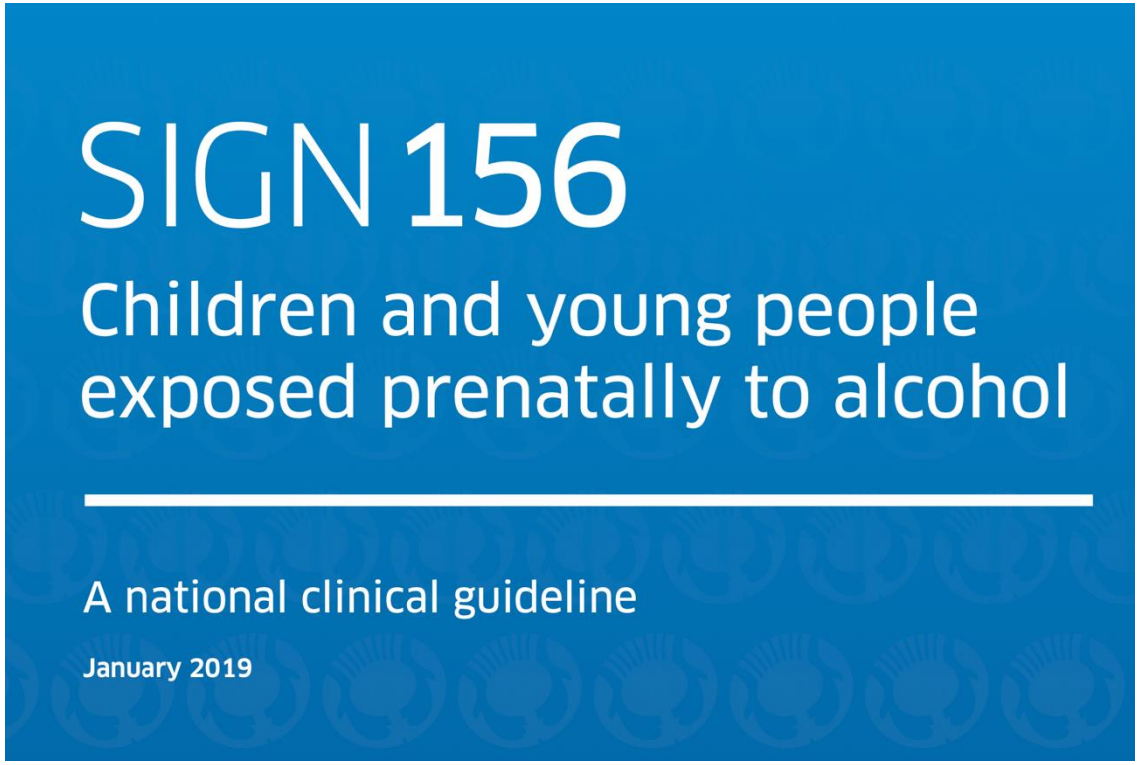
- Fetal Alcohol Spectrum Disorder is a neurodevelopmental condition with lifelong cognitive, emotional and behavioural challenges.
- FASD is caused by exposure to alcohol in utero. In addition to effects on the brain, FASD is a full-body diagnosis that can include more than 400 known conditions.
- 40% of women in the UK use alcohol during their pregnancy.
- Roughly 3% of the population has FASD – in every school in every year group there may be 1-2 children who have undiagnosed FASD.
- FASD affects more people than autism and is sadly most often undiagnosed or misdiagnosed. Early diagnosis and appropriate support are life-changing for those with FASD.
- Adult patients with FASD may experience continual issues with social relationships, mental health, employment, housing instability or substance misuse and may need referral for extra support and benefits.

Why focus on primary care?

- We can help prevent FASD. We can help diagnose it & help people with FASD get appropriate support. GPs are seen as being on the frontline of FASD prevention, diagnosis and support.
- Alcohol causes the problem, not the mother - need to de-stigmatise, no woman aims or wants to harm her baby.
- We are seeing it, whether we know it or not, in a variety of presentations in all age groups & often co-occurs with Autism & ADHD.
- Individuals with FASD are x19 more likely to encounter the Criminal Justice System than those without and x19 more likely to attempt suicide.

NICE & SIGN GUIDANCE





- NationalFASD

NATIONAL ORGANISATION FOR FASD

FASD POLICY MATTERS
NICE QUALITY STANDARD

NICE

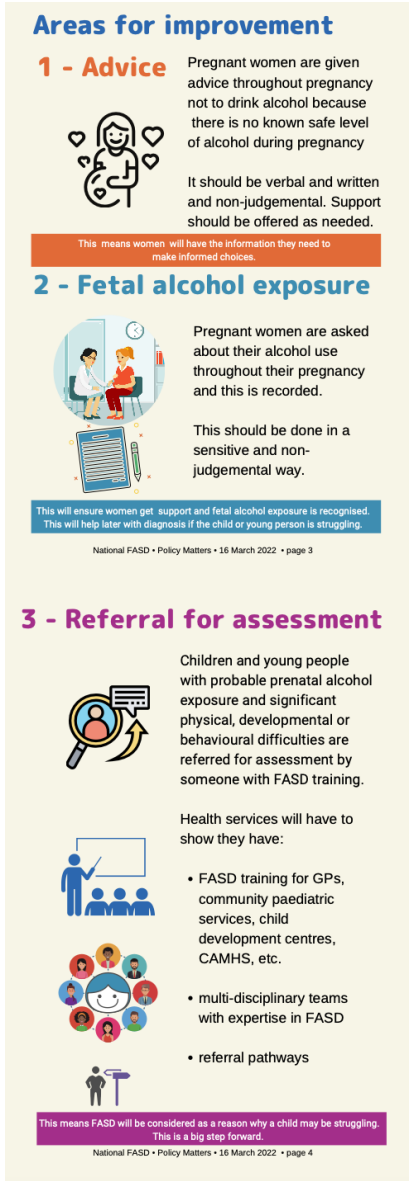
The National Institute for Health and Care Excellence (NICE) has issued a new **Quality Standard on FASD.**

It identifies areas for improving care, including:

• Assessing and diagnosing fetal alcohol spectrum disorder (FASD) in children and young people.

• Support during pregnancy to prevent FASD.

For the first time in England and Wales, local areas will have to show what they are doing to improve FASD services for children and young people.



Areas for improvement

1 - Advice

Pregnant women are given advice throughout pregnancy not to drink alcohol because there is no known safe level of alcohol during pregnancy

It should be verbal and written and non-judgemental. Support should be offered as needed.

This means women will have the information they need to make informed choices.

2 - Fetal alcohol exposure

Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded.

This should be done in a sensitive and non-judgemental way.

This will ensure women get support and fetal alcohol exposure is recognised. This will help later with diagnosis if the child or young person is struggling.

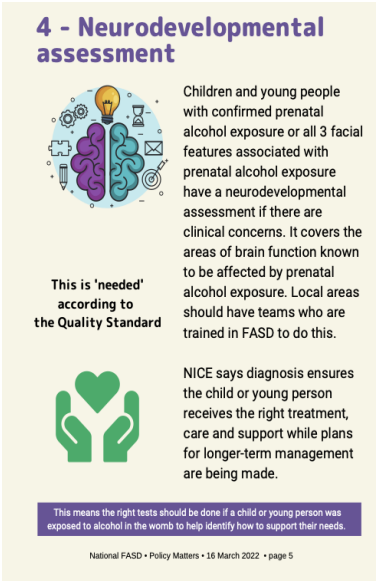
3 - Referral for assessment

Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment by someone with FASD training.

Health services will have to show they have:

- FASD training for GPs, community paediatric services, child development centres, CAMHS, etc.
- multi-disciplinary teams with expertise in FASD
- referral pathways

This means FASD will be considered as a reason why a child may be struggling. This is a big step forward.



4 - Neurodevelopmental assessment

Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns. It covers the areas of brain function known to be affected by prenatal alcohol exposure. Local areas should have teams who are trained in FASD to do this.

This is 'needed' according to the Quality Standard

NICE says diagnosis ensures the child or young person receives the right treatment, care and support while plans for longer-term management are being made.

This means the right tests should be done if a child or young person was exposed to alcohol in the womb to help identify how to support their needs.

5 - Management plan

Children and young people with FASD will have a management plan to help address their needs.

An individualised management plan sets out the intervention and support needs identified during assessment and diagnosis of FASD. It:

- Address basic and immediate needs and longer-term needs
- Anticipate upcoming problems
- Coordinate care across health, education and social services
- Be revised at times of transition

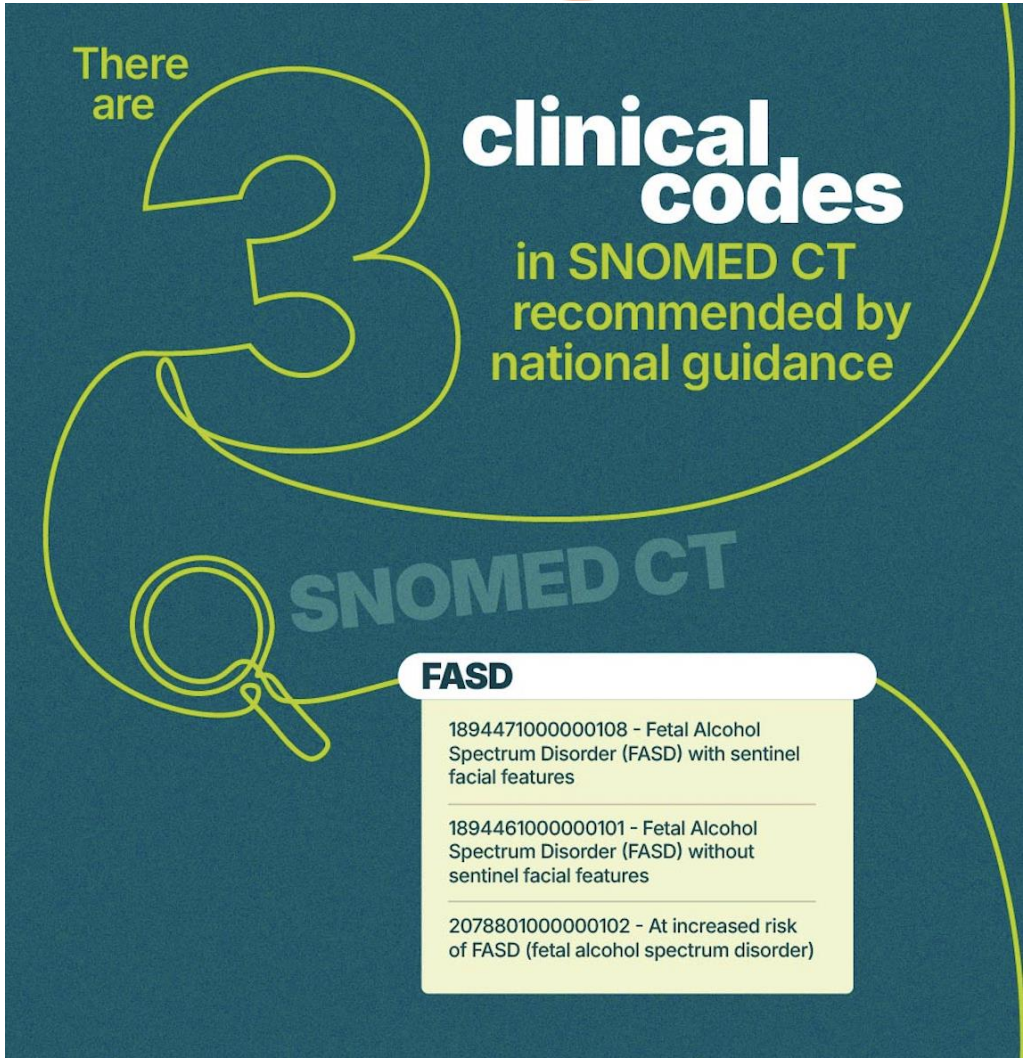
This means if a child or young person has FASD, there should be a plan for how to get the right support and help across services.

New Recommended SNOMED Codes

1. **Fetal Alcohol Spectrum Disorder with sentinel facial features** - formerly Fetal Alcohol Syndrome

2. **Fetal Alcohol Spectrum Disorder without sentinel facial features** - formerly Partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related neurological Disorder (ARND), Alcohol-Related Birth Defects (ARBD), or Neurobehavioural Disorder-Prenatal Alcohol Exposure (NDPAE).

3. **At increased risk of FASD** (Fetal Alcohol Spectrum Disorder)



Don’t Panic!

- GPs aren’t being asked to diagnose FASD
- But there are things we can do to help……

ADVISE & ASK

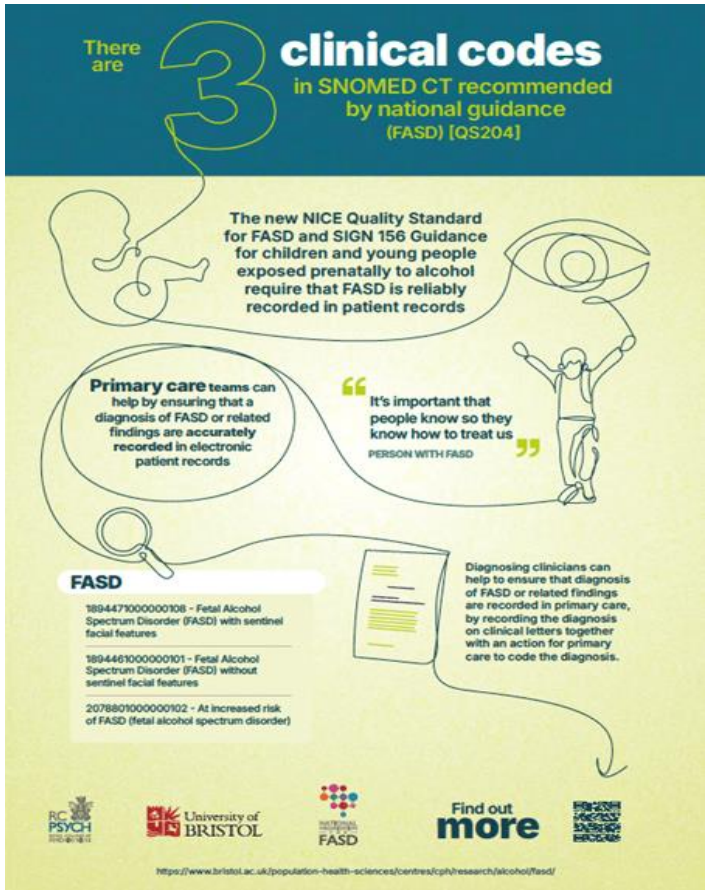
- **ADVISE** that there is **no safe alcohol limit in pregnancy** & offer support in reducing and stopping drinking before or asap during pregnancy (via referral to drug & alcohol service if necessary)
- **ASK** all pregnant women (and pre-conceptually) about alcohol consumption and record.

How/what to ask

- Is it ok for me to ask what life was like for you before and around the time you became pregnant?
- Could I ask if it was it a planned pregnancy? Did you take any prescribed medication? Did you smoke cigarettes? Did you drink alcohol? Did you use recreational drugs, such as cannabis?
- Did you make any lifestyle changes when you discovered you were pregnant? E.g. Taking vitamins, stopping eating or drinking certain things?
- Did you celebrate any special occasions after you found out you were pregnant?
- Would it be ok to discuss your use of alcohol?
- Are/were you aware of the risks associated with drinking alcohol during pregnancy?
- What did you drink at the time e.g. spirits, lager, wine etc? How often would you drink alcohol? At home or when you were out socialising? How much would you drink e.g. a large glass of wine, size of glass.

Code & Document

- **Document** in someone's notes if there is a history of fetal alcohol exposure or a diagnosis of FASD using the newly agreed SNOMED CT **codes** as recommended by NICE:
- **1894471000000108 - Fetal Alcohol Spectrum Disorder (FASD) with sentinel facial features**
- **1894461000000101 - Fetal Alcohol Spectrum Disorder (FASD) without sentinel facial features**
- **2078801000000102 - At increased risk of FASD (Fetal alcohol spectrum disorder)**
- This can be done by admin as part of scanning/coding documents or by clinical staff when reviewing a child/mother



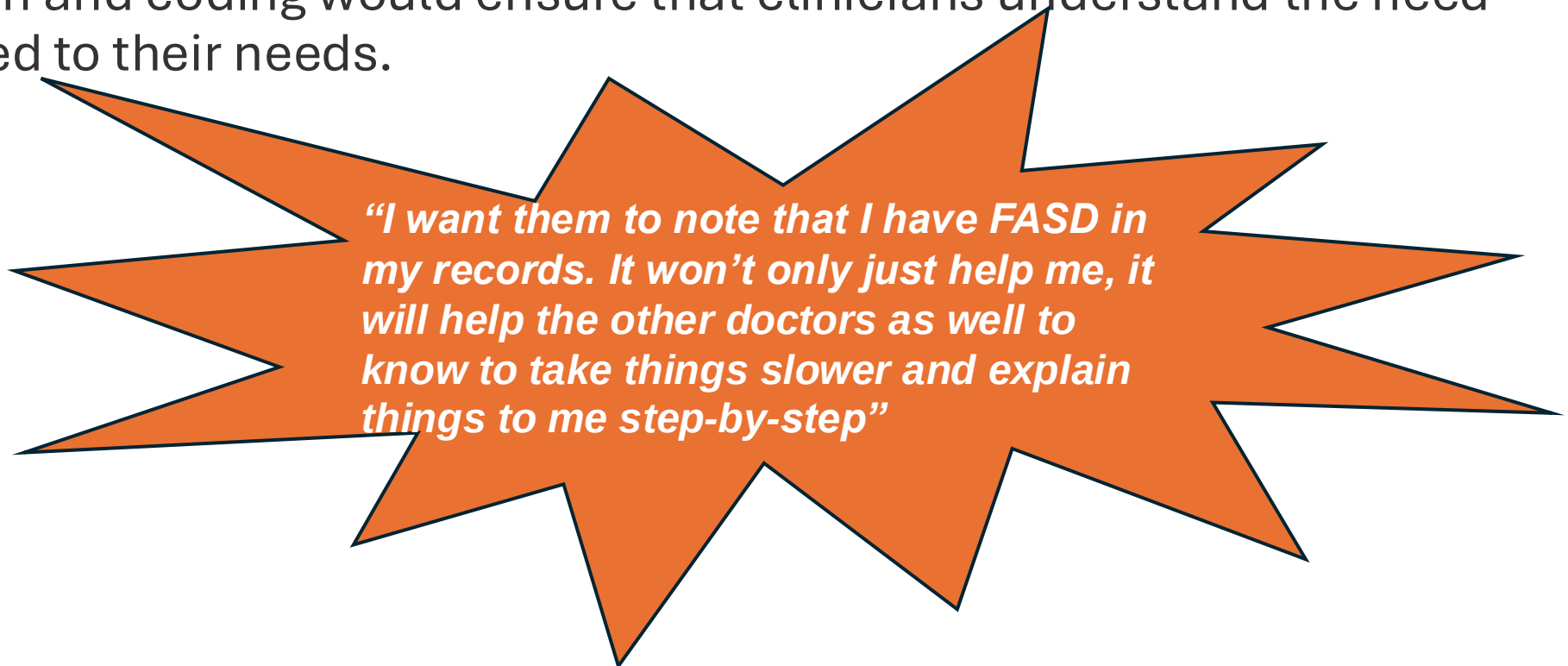
Share

- **Share** the diagnosis, clinical information and any concerns with other professionals when appropriate e.g. if making referrals, writing letters or reports, in MDTs or professional conversations.
- Lots of people with FASD are mis-labelled as having other neurodisabilities or behavioural problems because questions are not asked about fetal alcohol exposure and information about it is not shared amongst professionals.

Coding FASD…. helps people with FASD

- The absence of FASD in their records often leads to "*uncomfortable and unnecessary conversations*" and makes navigating healthcare more challenging.

- Proper documentation and coding would ensure that clinicians understand the need to provide care tailored to their needs.



Coding FASD…. helps clinicians

- Enhanced recording supports the implementation of the NICE Quality Standard for FASD, which is aimed at improving diagnosis and care pathways.

✓ *Statement 1:* Pregnant women are given advice throughout pregnancy not to drink alcohol.

✓ *Statement 2:* Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded.

✓ *Statement 3:* Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment.

✓ *Statement 4:* Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.

✓ *Statement 5:* Children and young people with a diagnosis of Fetal Alcohol Spectrum Disorder (FASD) have a management plan to address their needs.

Coding FASD…. helps with data & research

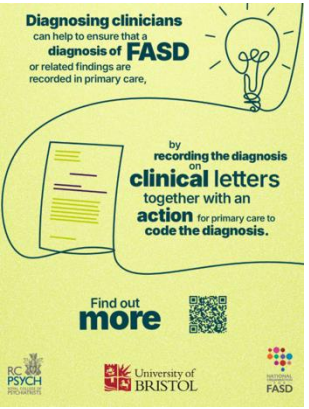
- Improved documentation would address significant gaps in data on FASD, enabling researchers and healthcare providers to better understand the prevalence and impact of FASD, ultimately leading to improved prevention and support strategies.
- Government policy says that local areas are responsible for providing FASD services but the FASD Not Commissioned report shows that the majority of ICBs & Trusts have a slow, non-strategic uncoordinated response to the NICE QS204 and hence are missing a golden opportunity to protect baby's brains. There are pockets of hope but systemic confusion.
- We need to encourage our commissioners to ramp up FASD services – urgent attention needs to be given as to how to set up FASD diagnosis pathways with increased training available.
- We need cross-sectoral thinking and planning, data and research can help advocate for this.

Knowledge Mobilisation Bit

- In collaboration with the University of Bristol we brought together stakeholders (paediatricians, GPs, data specialists, 3rd sector & researchers) to explore the barriers & facilitators to FASD diagnosis & recording.
- The goal was to develop strategies for improving the uptake, consistency and accuracy of FASD coding in electronic patient records.
- GPs interviewed for the project, particularly those less familiar with FASD, highlighted the need for accessible guidance and support. They noted that they would be more likely to document FASD if diagnosing specialists clearly outlined this action in clinical letters.

- They also mentioned that other trained team members, not just doctors, often code diagnoses, underscoring the need for materials addressing the broader primary care team.

- With the insights from these discussions, we collaborated with a design partner to create a one-minute video and infographics featuring quotes (downloadable here) from individuals living with FASD and references to the latest FASD guidelines.
- These materials suggest clear actions for primary and secondary care teams to improve clinical coding practices.
- The Royal College of Psychiatrists and the National Organisation for FASD have endorsed these resources, which are available to view, download and share on our project website and Open Science Framework pages.


Diagnosing clinicians
can help to ensure that a
diagnosis of FASD
or related findings are
recorded in primary care,
by
recording the diagnosis
on
clinical letters
together with an
action for primary care to
code the diagnosis.
Find out
more
University of
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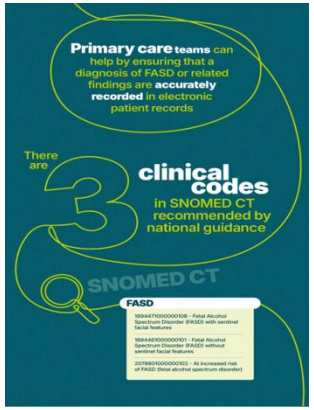
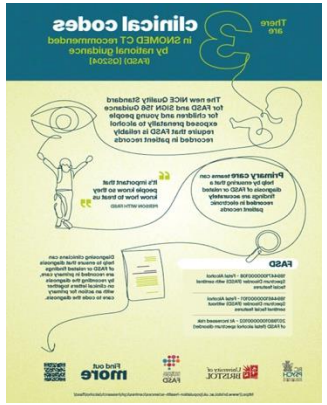
FASD


Primary care teams can
help by ensuring that a
diagnosis of FASD or related
findings are accurately
recorded in electronic
patient records
There
are
3
clinical
codes
in SNOMED CT
recommended by
national guidance
SNOMED CT
FASD

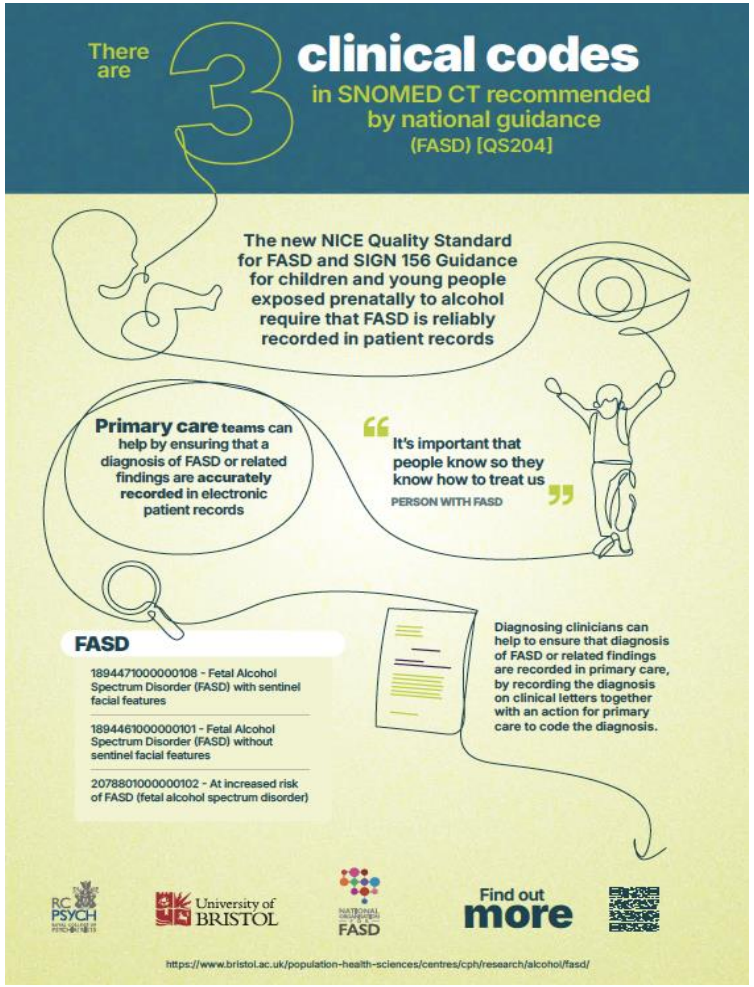


Snazzy bit


It's important that
people know so they
know how to treat us
PERSON WITH FASD

Take Home Messages

- **Advise & Ask**
- **Code & Document**
- **Share**



Training

- If you are interested in training, please contact FASD UK by emailing training@nationalfasd.org.uk, they can help arrange bespoke training for protected learning time – involving the country's leading FASD experts.
- FASD Awareness run webinars, training events & workshops
- FASD Network UK

FASD AWARENESS
FOETAL ALCOHOL SPECTRUM DISORDERS

NATIONAL ORGANISATION FOR FASD

Resources

- NICE FASD QS204
- Improving Clinical Coding for FASD – University of Bristol
- OSF Home – Improving Clinical Coding for FASD
- Recognizing the Hidden Disability of fetal Alcohol Spectrum Disorder (FASD) in Electronic Patient Records
- FASD Health Needs Assessment (2021) DHSC
- SIGN 156: Children and Young People Exposed Prenatally to Alcohol – A national clinical guideline.
- Not Commissioned – Systemic Confusion in NHS services for alcohol, pregnancy and FASD
- The Time Is Now: The National Perspective on Ramping Up FASD Prevention, Diagnosis and Support Services
- Psychiatrist Primary Care Knowledge Boost podcast – Neurodevelopmental Disorders in children (focus on FASD) with Consultant r Raja Mukherjee
- FASD UK Professionals Facebook Group (part of FASD UK Alliance)
- Me & My FASD

Thank you for your time.

- Any questions? Please feel free to email me at:

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FASD Song & self-portraits