

# Press release: Expert committee recommends trial period to test babies for SCID

Following a review of the evidence, the independent expert screening committee recommends that screening for severe combined immunodeficiency (SCID) should be tried for a period of time in the NHS.

SCID refers to a number of rare inherited conditions which affect the development of a baby's white blood cells – these are an important part of the immune system and make it difficult for babies to fight infections. Around 15 to 25 babies are born with the condition every year in the UK. The treatment is a bone marrow transplant, which can repair the damaged immune system.

The trial period will allow the committee to gather information about the practicalities and likely effect of screening before a final recommendation is made on whether to include SCID in the NHS newborn bloodspot screening programme.

Screening, as part of the newborn blood spot screening programme, would look for babies with low numbers of white blood cells as a sign that they may have SCID, but the independent committee found that more evidence is required on whether screening for the condition would do more good than harm, as it is not clear:

- how many babies may be diagnosed with having the condition when they do not (false positives)
- what care and treatment to offer babies with other conditions that cause low numbers of white blood cells

Professor Anne Mackie, Director of Programmes for the UK National Screening Committee (UK NSC), said:

There is still uncertainty whether screening for SCID would lead to babies who are well being diagnosed with the condition and receiving unnecessary treatment. It's also unclear what would be the best care and treatment to offer babies who don't have SCID, but are found to have other immune deficiency conditions.

We need to find out if screening for SCID would provide overall benefits or do more harm by falsely diagnosing those without the condition. That is why the committee has recommended screening over a trial-period which will help them decide whether NHS screening for SCID should be recommended.

After careful consideration of the evidence, the UK NSC did not recommend

introducing screening programmes for the following conditions:

## **Newborn screening for Cytomegalovirus (CMV)**

Cytomegalovirus is a common viral infection found in children and adults which doesn't always have symptoms nor need to be treated. If it is passed from mother to baby during pregnancy this is called congenital CMV infection. Screening was not currently recommended as it is not possible to know which babies are going to develop long-term health problems. So more research is needed to distinguish between babies that will suffer from the infection and babies that will not.

## **Human T-cell lymphotropic virus (HTLV) in pregnancy**

Human T-cell lymphotropic virus (HTLV) can be passed from person to person through blood transfusion or unprotected sexual contact. HTLV infection can also be passed from mother to child. This is usually through breastfeeding for longer than 6 months. Screening was not recommended as the risk of a mother passing HTLV to their child through breastfeeding is low unless breastfeeding is continued beyond 6 months.

## **Newborn screening for biliary atresia**

This is a rare condition that causes the bile ducts to become blocked or inflamed. Bile is a digestive fluid necessary to digest fatty acids and vitamins. If it cannot drain away from the liver, bile can build up and cause serious liver damage in the early years. Screening was not recommended as there is no reliable test which could be used to find babies with biliary atresia in the first week of life.

## **Iron deficiency anaemia (IDA) in children under 5 years**

IDA is the most common form of anaemia and occurs when iron levels are too low to support the production of red blood cells, usually because of a lack of iron in the diet. Children aged under-5 are especially at risk. It is possible that IDA may affect a child's development, but this is not known for certain. Screening was not recommended as it is not known how many children in the UK are affected. It is uncertain whether IDA in children under the age of 5 causes adverse developmental outcomes and whether it gets better without treatment. Also a suitable test is not yet available.

The UK NSC will review all these recommendations again in 3 years as part of its regular evidence review process or earlier if significant new evidence becomes available.

The latest screening recommendations were made at the UK NSC meeting on 25 October 2017, the [minutes of which are published today](#) (6 December 2017).

## Background

1. The [UK National Screening Committee](#) is independent of, but supported by, Public Health England.
2. View the detailed [summaries of the recommendations](#) for all of the conditions mentioned.
3. Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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## [Press release: New research shows desperate dieters in danger – the secret world of online slimming pills](#)

Online sellers of potentially dangerous slimming pills containing withdrawn pharmaceutical ingredients are putting desperate dieters' health at serious risk by seducing them with the promise of quick-fix weight loss and discreet deliveries that bypass discussions with their GP and pharmacist, new research reveals.

One in three slimmers have tried slimming pills purchased online, according to the joint #FakeMeds survey of 1,805 slimmers by the Medicines and Healthcare products Regulatory Agency and Slimming World. Since April 2013, the Agency has seized nearly £4 million worth of dodgy weight loss pills.

Three quarters of slimmers (77%) were enticed by promises of rapid weight loss, more than half were attracted to being able to order discreetly (57%) and more than four in ten (44%) ordered online because they didn't want to speak to a GP or pharmacist, the survey revealed.

However, almost two-in-three (63%) suffered unpleasant side effects after

taking slimming pills bought online. These side effects included diarrhoea, bleeding that wouldn't stop, blurred vision and heart problems. Worryingly, four out of five (81%) didn't report these side effects to anyone.

The potentially dangerous products seized by the Agency are not tested for safety and have been found stored in dirty, rat-infested warehouses and garden sheds. In 2016, MHRA seized more than 4.6 million fake medical products and closed more than 5,000 websites selling medicines illegally.

Four out of 10 respondents said they had used the slimming pills knowing there were health risks, with more than six out of ten (62%) doing so because they were 'desperate to lose weight'.

Sarah-Jayne Walker, who became obsessed with slimming pills bought online before quitting her habit and eventually joining Slimming World, said:

I used to spend hours searching the web for what I thought were the right diet pills, ones that said they would work straight away and that had the best reviews. My mind became consumed with those pills...

However, after suffering heart palpitations, IBS, sickness, light headedness and even fainting, I knew I had to get a grip and sort my mind out. I joined Slimming World at the end of May and it has been a revelation.

I don't have to punish myself or feel guilty for eating anymore and I've lost just over two stone. The support has been amazing and I can't tell you how proud I feel of myself.

The majority of diet products are regulated as foods, however MHRA regularly seizes products that contain withdrawn pharmaceutical ingredients due to risks of heart attacks and strokes.

MHRA Senior Policy Manager, Lynda Scammell, said:

Quick fixes for losing weight may have serious health consequences in the short or long term, including organ failure and death.

It's essential you know what you're buying online and what the risks are. If you don't, your weight could end up being the least of your worries!

If you're looking to buy medicines online, check if the seller is registered by using our easy online checking system, [www.gov.uk/fakemeds](http://www.gov.uk/fakemeds) or check if they display the distance selling logo.

If you think you've bought fake medical products, please let us

know via [www.gov.uk/fakemeds](http://www.gov.uk/fakemeds). This way we can use the information to continue to seize these products and close websites that are putting public health at risk.

There are reputable groups out there that can support you to lose weight through healthy lifestyle changes. Your GP or healthcare professional will be able to advise you on finding the right option for you.

Jenny Caven, Slimming World's Head of External Affairs, said:

It's easy to see how quick fix promises made by the sellers of online slimming pills could seem tempting to people who are desperately struggling with their weight.

Buying slimming pills online can be incredibly risky though. The sellers are often unregulated and taking the pills puts people at risk of dangerous side effects. Learning to make changes to the way you shop, cook and eat and getting support to develop new healthy habits really is the best way to lose weight. Not only is it safer, it's also far more satisfying and has the added benefit that newfound habits can be passed on to the people around you too. Getting support makes your new habits more likely to stick in the longer term and you won't suffer any nasty side effects.

The #FakeMeds survey highlights how easy it is for people to buy potentially dangerous slimming pills online. Therefore, the Medicines and Healthcare products Regulatory Agency is working in partnership with Slimming World as part of the Agency's #FakeMeds Campaign to encourage those wanting to lose weight to turn to safe, legitimate and appropriate routes.

The #FakeMeds campaign website has a range of easy and quick top tips to keep yourself safe online. [www.gov.uk/fakemeds](http://www.gov.uk/fakemeds)

If you would like to hear more about the healthy weight loss support that Sarah-Jayne experienced please visit [www.slimmingworld.co.uk](http://www.slimmingworld.co.uk)

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## **Press release: MHRA reclassifies Viagra Connect tablets to a Pharmacy medicine**

The Medicines and Healthcare products Regulatory Agency (MHRA) has today announced Viagra Connect (containing sildenafil 50mg) will be [formally classified](#) from a prescription only medicine (POM) to a pharmacy medicine (P). This means it could be available without prescription for use by men over 18 who have erectile dysfunction.

This decision was made following a reassuring assessment of the safety of the Viagra Connect, advice from the Commission on Human Medicines, and a public consultation earlier this year with positive outcome.

If marketed, the medicine will be sold from pharmacies following a discussion with the pharmacist. Pharmacists will be able to determine whether treatment is appropriate for the patient and can give advice on erectile dysfunction, usage of the medicine, potential side effects, and if further consultation with a general practitioner is required.

Viagra Connect will not be sold to those with severe cardiovascular disorders; at high cardiovascular risk; liver failure; severe kidney failure; or taking certain interacting medicines. Use of Viagra Connect in these groups of men must continue to be under the supervision of a doctor.

Making this medication more widely available will help direct men who might not otherwise seek help into the healthcare system and away from the risks that come with buying medicines from websites operating illegally.

Erectile dysfunction medicines are a popular target for criminals selling unlicensed and counterfeit medicines. Over the past 5 years, investigators from MHRA have seized more than £50 million of unlicensed and counterfeit erectile dysfunction medicines.

Mick Foy, MHRA's Group Manager in Vigilance and Risk Management of Medicines, said:

This decision is good news for men's health. The move to make Viagra Connect more widely accessible will encourage men to seek help within the healthcare system and increase awareness of erectile dysfunction.

Erectile dysfunction can be a debilitating condition, so it's important men feel they have fast access to quality and legitimate care, and do not feel they need to turn to counterfeit online supplies which could have potentially serious side effects.

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# Press release: Men and women asked not to miss out on bowel screening

PHE is calling on all men and women, aged over 60, to get screened for bowel cancer after the latest figures show over 40% are not getting tested – with embarrassment over providing a stool sample one of the reasons, among men in particular, that is putting thousands unnecessarily at risk of dying.

PHE wants wives, partners and daughters to encourage the older men in the family – as well as the women – to overcome any embarrassment and ensure they send in a sample to be tested.

A new PHE report today (24 November 2017), [Screening Programmes in England 2016 to 2017](#), shows that despite a 3% increase on the previous year, the take-up for bowel cancer screening (59%) is still significantly lower compared to other cancer screening programmes – breast screening (76%) and cervical screening (72%).

Bowel cancer screening is offered to all men and women aged 60 to 74, who are sent a home test kit to provide stool samples.

There were over 3,000 bowel cancers diagnosed as a result of screening in 2016 to 2017. In over 90% of these cases, cancers were found at an early stage, where treatment is more likely to be successful.

Bowel cancer is the fourth most common cancer in England, but the second leading cause of cancer deaths, with around 13,000 people dying from it every year.

If detected early, bowel cancer is very treatable which is why screening is vital and it has been shown to reduce the risk of dying from bowel cancer by 16%. Thousands more lives could be saved if more people, particularly men, returned their stool samples to be tested.

Improvements are being made to make screening easier and next year there will be a new home test, the faecal immunochemical test (FIT), which requires just 1 sample rather than the current 3, and will detect bowel cancer more accurately.

In addition to the home test, a one-off test called bowel scope screening is offered to men and women at the age of 55.

Professor Anne Mackie, PHE's director of screening, said:

It's of great concern that 4 out of every 10 over 60 year olds are not taking up the offer of getting tested for bowel cancer. Men in particular are less likely to send in a sample, so we're asking their partners, children and grandchildren to encourage them to do so.



Bowel cancer causes 13,000 deaths every year, which is why screening is so important. Embarrassment over giving a stool sample may be causing thousands of preventable deaths. But with a new home test kit next year making it much easier to get screened, we are hoping to see numbers increase.

Judith Brodie, Interim Chief Executive at Beating Bowel Cancer, said:

People may feel uncomfortable completing their home screening tests, but they can be crucial in the early diagnosis of bowel cancer – which is very treatable if caught early. We strongly encourage the use of these bowel screening tests – they can be life-saving.

PHE is committed to improving bowel cancer screening attendance and has a programme of work which includes:

- providing local services with clearer information to encourage better screening take-up
- encouraging GPs to endorse screening invitation letters

The Bowel Cancer Screening Programme, recommended by the UK National Screening Committee, began in 2006 and the expert Committee has reviewed the evidence every 3 years. The Committee recommends the programme as it shows clear benefits and saves lives. Screening remains a choice, based on a person's individual circumstances.

## **Background**

1. The risk of bowel cancer increases with age, with over 80% of bowel cancers arising in people who are 60 or over.
2. Bowel scope screening, also known as flexible sigmoidoscopy, is a one-off test offered to men and women at the age of 55. It is normally used as a routine outpatient appointment procedure to examine the inner lining of the lower large intestine – the part where most cancers are found. It can also be used to evaluate gastrointestinal symptoms, such as abdominal pain, rectal bleeding, or changes in bowel habit.
3. The NHS Bowel Cancer Screening Programme offers screening every 2 years to all men and women aged 60 to 74. People in the invitation age range are automatically sent an invitation, then their screening kit, so they can do the test at home. Those over the invitation age range can ask for a screening kit every 2 years by calling a Freephone number – 0800 707 60 60.

4. PHE is currently working with NHS England on the introduction of a new home test kit, the Faecal Immunochemical Test (FIT), which can quantify the amount of blood found in a stool sample. It has a number of potential advantages over the current test, faecal occult blood (FOB), as it is more accurate and more acceptable to use.
5. Anyone with any symptoms, such as a persistent change in bowel habit or bleeding from the back passage, or who has concerns about their bowel health, should speak to their GP, who can arrange for a referral with a specialist, if necessary.
6. For more information about the bowel cancer screening programme, [visit NHS Choices](#)
7. [Public Health England](#) exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and providing specialist public health services. We are an executive agency of the Department of Health, and are a distinct organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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## **[Press release: Help make medicines safer by reporting suspected side effects: MHRA launches campaign](#)**

From 20-24 November, MHRA is running a social media campaign to promote recognition and reporting of suspected side effects from over-the-counter medicines, as part of an EU-wide awareness week.

While medicines are safe and effective, side effects can happen, even with over-the-counter medicines. It is important the risks associated with all

medicines are understood and communicated to health professionals and patients.

Potential side effects may range from a headache or sore stomach, to flu-like symptoms or just 'feeling a bit off' and reporting these can help regulators monitor medicines on the market and take action as appropriate.

Regulators such as MHRA rely on the reporting of suspected side effects to make sure medicines on the market are acceptably safe. Unfortunately, all reporting systems suffer from under reporting – this is why our campaign is important to both raise awareness and help strengthen the system.

### [SCOPE ADR Campaign](#)

Mick Foy, Group Manager for MHRA's Vigilance and Risk Management of Medicines division, said

The most important part of our work is making sure the medicines you and your family take are effective and acceptably safe.

Our campaign will help the public, patients and healthcare professionals report potential side effects and have confidence that their reports are making a difference.

You can help make medicines safer by reporting any suspected side effects easily and quickly online through the [Yellow Card Scheme](#).

The campaign is part of the Strengthening Collaboration for Operating Pharmacovigilance in Europe (SCOPE) Joint Action project. One of its main aims is to raise awareness of national reporting systems for suspected side effects in medicines.

### **Notes to Editor**

1. National reporting systems for the collection of suspected adverse drug reactions (commonly known as side effects) have acted as early warning systems to help identify numerous important safety issues, many of which were not recognised as being related to a particular medicine until reports were received by medicines regulators.
2. The Medicines and Healthcare products Regulatory Agency is responsible for protecting and improving the health of millions of people every day through the effective regulation of medicines and medical devices, underpinned by science and research. The agency consists of three centres: CPRD, NIBSC and MHRA.
3. The public is advised that they should take prescription-only medicines after an appropriate consultation with their GP. Only healthcare professionals can take into account risks and benefits associated with

every medicine.

4. To report a counterfeit medicine or device contact MHRA's dedicated 24-hour hotline on 020 3080 6701, or email [counterfeit@mhra.gov.uk](mailto:counterfeit@mhra.gov.uk), or write to: Counterfeits, The Intelligence Unit, MHRA, 151 Buckingham Palace Road, Victoria, London, SW1W 9SZ.
5. To report a suspected side effect from an unlicensed medicine visit the [Yellow Card Scheme](#)
6. The SCOPE Joint Action project ([scopejointaction.eu](http://scopejointaction.eu)) social media campaign is being taken forward through the Heads of Medicines Agencies Working Group for Communications Professionals.

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