

# Press release: Screening committee recommends trial of testing 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.
- 

## News story: SMEs encouraged to form new health and social care marketplace

The Government is encouraging technology-based small and medium-sized enterprises (SMEs) to supply to the public sector via a new marketplace for health and social care providers.

NHS Digital and Crown Commercial Service (CCS) have created a new Dynamic Purchasing System to provide consumers access to companies that supply Health and Social Care Network (HSCN) services. The DPS is now live, and will continue to grow as suppliers join throughout the term.

HSCN enables health professionals from NHS Trusts, hospitals, GPs, social care organisations and non-public sector bodies to communicate and share information, delivering efficient, effective public services that meet the needs of citizens.

### A new network

For the last 13 years, a network previously known as N3 (New National Network) connected the NHS. N3 will be succeeded by HSCN – a network for all health and social care organisations, allowing any supplier that can become HSCN-compliant to provide services.

HSCN could be worth up to £500 million over the next six and a half years.

Niall Quinn, CCS Strategic Director for Technology said:

We aim to create a vibrant and dynamic marketplace that increases choice for health and care providers while encouraging competition between a greater number and range of suppliers, including SMEs.

All suppliers have to be HSCN Stage 1 compliant to join the DPS. The DPS application process has been simplified and removes the traditional lengthy framework tender process, removing the cost and resource required for that process.

Once on board, suppliers will be able to bid to deliver the service to thousands of public sector organisations across the UK.

Dermot Ryan, HSCN Programme Director says

Creating a competitive market for network services in health and social care, to drive both product innovation and value for money, has been an ambition of the HSCN programme since the outset. Working in partnership with Crown Commercial Service, the establishment of the HSCN dynamic purchasing system is a significant part of realising this ambition. The DPS will promote the formation of a thriving market in HSCN services and provide health and social care customers with an easy to use, low risk way of procuring compliant services.

## **Opportunity for small businesses**

The move away from a framework model to the DPS was with suppliers and particularly SMEs in mind, reducing certain barriers to entry and enabling compliant suppliers to join over time.

Supplier feedback was positive on this move, with Ian Fishwick, Chief Executive of Adept Telecom, Commercial Director for Innopsis, and member of the Cabinet Office SME Panel commenting:

The new Dynamic Purchasing System for the Health and Social Care Network is a great example of how this form of procurement can be used for complex requirements. Previously many believed that DPS were only suitable for buying commodity products and this is now demonstrably not true.

One of the problems SMEs have with conventional frameworks is that if you miss the start then you are effectively cut out of the market for several years. With the HSCN Dynamic Purchasing System we have shown that businesses who comply over time can join in when they are ready.

To find out more about HSCN, visit [the NHS Digital HSCN webpage](#)

To find out how to sign up to provide services through HSCN, [visit the DPS webpages](#)

---

## **Press release: New guidance for fishermen ahead of next phase of the discard ban**

The next phase of the landing obligation, also known as the 'discard ban', comes into force from 1 January 2018.

The Marine Management Organisation [has provided guidance](#) for the fishing industry to help them comply with the next phase of the discard ban. This outlines which fish come under the landing obligation, what fishermen have to do with them on board, and which can be sold for human consumption.

The new developments will see more fishing vessels captured by the landing obligation as thresholds for inclusion are reduced or removed for some fish species. There are also changes around exemptions for some vessels, in particular where scientific evidence indicates that an increase in selectivity of species is hard to achieve and around unwanted catches for certain gear types.

For 2018, the UK Government has worked to maintain, and in some cases extend, exemptions allowing fish with high survival rates to be discarded as well as some unwanted catches that are difficult to avoid. In addition, the MMO will continue to apply a fair and proportionate approach to enforcement.

The development is the latest phase of the wider discard ban which will bring an end to the practice of throwing dead fish back into the sea. The landing obligation was initially introduced in January 2015 for certain pelagic fisheries. All quota species will be phased in under landing obligation rules by 2019.

Guidance on the [landing obligation](#) can also be found on the European Commission's website.

Financial support from the European Maritime Fisheries Fund (EMFF) may be available to help fishermen adapt and comply with the landing obligation. Further information is available on [the MMO website](#).

---

## **Press release: Government and FCA**

# crack down on older pension scheme charges

The saving over the past 4 years revealed today (6 December 2017) means high charges levied on members of older workplace, or legacy, pension schemes, are soon expected to be a thing of the past.

A report published by an Independent Project Board, commissioned to investigate high charges, found that £25.8 billion of assets in defined contribution workplace pension schemes were potentially exposed to charges of more than 1%, failing to give savers value for money. This has now been reduced by over 90%.

Since 2013, the government and the Financial Conduct Authority (FCA) have worked closely with these pension providers to bring their legacy schemes in line with the standards of new workplace pension schemes introduced since the launch of automatic enrolment.

Guy Opperman, Minister for Pensions and Financial Inclusion, said:

No one that saves into a pension scheme should have concerns that their savings are at risk of being eroded by excessive charges.

That's why we are tipping the balance back in favour of consumers, who will now see their schemes delivering better value and increasing their income in retirement.

By working closely with regulators and providers, we are committed to getting consumers the best possible deal.

The Independent Project Board found that these pension schemes, which are contract and trust-based and not covered by the government's pension charge cap on workplace pension schemes used for automatic enrolment, were charging excessive amounts for annual administrative charges, without justifying the extra costs.

Of the £25.8 billion of assets covering 1.5 million pension pots, between £5.6 billion and £8 billion was potentially exposed to charges above 2%, and nearly £1 billion to charges above 3%, with the latter often members with small pension pots worth less than £10,000.

The government and FCA continue to work with the small number of remaining providers to eliminate high costs and charges by the end of 2018, and has been clear that it will legislate, if necessary.

This is the next step government is taking to ensure savers receive good value for money from their pension, that their pension will meet their needs for retirement, and that savers are better able to maximise savings.

DWP and FCA published the most recent legacy audit report [Poor value workplace pension schemes: a review](#) in December 2016.

Follow DWP on:

---

## **Speech: Exchequer Secretary's speech launching Transforming Infrastructure Performance and Transport Infrastructure Efficiency Strategy**

[Check against delivery]

### **Introduction**

Thank you Robert.

It is an absolute pleasure to be here today (6 December 2017).

Not just because we are kick-starting a new and exciting agenda, but also because I get to launch it with my former boss, colleague and friend from the Department for Transport.

Thank you Minister for joining us.

Some of you in the room may already know me from my time at Transport.

And, despite my move to the Treasury, I am still essentially looking at the same question; how can infrastructure help us to grow our economy and boost productivity?

The new government programmes, [Transforming Infrastructure Performance](#) and the Transport Infrastructure Efficiency Strategy, that we are launching today form part of the answer.

But let me start by emphasising that I believe we are living through a new age.

It used to be that government would ask the question – why should we invest in infrastructure?

Now government asks – how can we best deliver that investment? And how can we realise the benefits of this investment quicker?

## **Productivity challenge**

Infrastructure has a vital role to play in boosting our national productivity.

Productivity growth has slowed across all advanced economies since the financial crisis.

But the OBR's recent downgrade of the productivity forecast reflects a long-term trend for the UK.

This is a challenge that has been decades in the making.

A challenge we urgently need to tackle.

For context, if we raise productivity growth by even one quarter of a percent on a sustained basis, we would add £56 billion to GDP. This in turn would raise wages and increase peoples' quality of life.

The productivity problem extends to all parts of the economy. In construction, we know that we face approximately a £15 billion productivity gap every year.

If we can make strides in closing this gap – transforming this sector into one which is closer to, say, manufacturing, which saw a 68% increase in its productivity over the last 20 years – I believe we will be able to meet this challenge head on.

For a sector that contributes 8% to the economy, small productivity gains could have a phenomenal impact.

We want construction to be more like the high tech manufacturing and automotive industries which have invested in R&D and automation and, in return, have benefitted from high productivity growth.

## **Record levels of investment**

Our recognition of what infrastructure can do for us is one of the reasons this government is investing at record levels.

We have already committed to a 50% increase in transport investment between 2015 and 2020.

We have extended the National Productivity Investment Fund to £31 billion, targeting investment at regional growth, improving transport links and building new houses in high demand areas.

We have also accepted the National Infrastructure Commission's recommendations to take action on the Oxford to Cambridge Corridor, investing up to £1 billion on East West Rail and agreeing a new housing deal with Oxfordshire that will deliver 100,000 homes by 2031.

The Infrastructure and Projects Authority (IPA) estimate that over the next



10 years, we expect to see total public and private investment to hit £600 billion.

This £600 billion National Infrastructure and Construction Pipeline includes a planned pipeline of investment valued at £462 billion.

Over £240 billion of which we expect to realise by the end of 2021.

In order to realise the benefits of all of this investment, we have to make sure we can deliver these projects as effectively and efficiently as possible.

Our plans have to be delivered on time and on budget.

As set out in the [Industrial Strategy](#), improving delivery is a key pillar of the government's strategy to build the modern and efficient infrastructure, which will support the economy and boosts productivity.

## **Delivery record**

We already have a delivery track record that we should all be extremely proud of.

Since 2010 we have delivered over 4,500 projects.

One project this year which I am particularly enthusiastic about is the Manchester Ordsall Chord, part of the Northern Hub.

It's a new and important link between Manchester Piccadilly and Victoria stations, generating new routes from Newcastle to Manchester Airport and enabling people to get into Manchester 30 minutes faster than before.

We also completed the new Francis Crick Institute this year, one of Europe's largest centres of biomedical research.

Its use of BIM [pronounced "bim", as in "tin"] enabled us to quickly design a new bespoke building, taking into account the complex site and sensitivity of the research.

The new M1/M6 Junction 19 improvement works is a £191 million project that was completed ahead of schedule, reducing congestion and creating new routes for people in the East Midlands.

This is a legacy we can build on, through the publication of these two new programmes today.

## **Improving delivery**

[Transforming Infrastructure Performance](#) (TIP) sets out how the government will improve the performance of infrastructure and boost productivity in both delivery and operation.

It's an ambitious plan to transform infrastructure delivery over the long-

term, using the government's influence to drive modern methods of construction so Britain can lead the world in high-tech building.

It's a plan which will signify a shift from focusing on driving down costs in the short term, to delivering value for taxpayers in the long term.

We want building infrastructure to deliver benefits for both the supply chain and for its end users, the public.

The Transport Infrastructure Efficiency Strategy (TIES) will ensure these plans translate into real change for the UK's biggest infrastructure sector.

Transport equates to 95% of all government spend on economic infrastructure – so it is important we get it right!

Through TIES we have nearly all transport delivery agencies on board. So we are halfway there already!

Our recent Budget announcement for a presumption in favour of offsite construction is already a significant milestone. It's a concept pioneered by HS2, and we now want to see it applied much further across government projects.

We have agreed with five of the biggest spending departments that their infrastructure projects would buy modern methods of construction wherever that delivers the right benefits and provides value for money to taxpayers.

We are creating the stable, critical mass that is needed to generate investment in modern methods and that industry has been asking for.

It also shows how government projects can be at the forefront of innovation.

TIP will support the policies announced at Budget aimed at improving construction project delivery.

These include £40 million announced to scale up innovative regional training models and £170 million allocated to help commercialising cutting edge digital and manufacturing technologies.

The government is bought in.

But for it to work, we know it will require investment in innovation and new thinking from within the sector too.

Through the Construction Sector Deal and stewardship of Andrew Wolstenholme, I believe we will start to see these changes come to fruition and the construction industry modernise.

We have already seen this happen in other parts of the economy, so I see no reason why we can't see the same for construction.

## **Conclusion**

But all of this gives me great hope.

Hope that instead of building less for more as we used to, we can start building more for less.

Hope that, by harnessing new technology and modern methods of delivery, we can have a thriving supply chain that is world leading and a delivery track record that is maintained.

Hope that, by government and industry coming together, we will begin to drive the transformation of the construction sector that we all want to see.

Thank you.