



Llywodraeth Cymru
Welsh Government

Valuing our health

Chief Medical Officer for Wales
Annual Report 2018/19



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Introduction

As Chief Medical Officer (CMO) for Wales I have three main duties: to advise ministers on health issues; to lead the medical profession in Wales; and to advocate for better health on behalf of the people of Wales. This is my third annual CMO report and, as in previous reports, I aim to cover a range of issues which I hope will be of interest and relevance to politicians, patients and the public.

This year's report begins by describing the health status of our nation. The good news is that health indicators are continuing to improve but the recent levelling off of life expectancy has attracted a lot of interest in the last year and is a trend which we need to understand better and continue to monitor carefully. Obesity levels in the population are at a worrying level with childhood obesity being a particular concern – I am currently developing a healthy weight plan for Wales and we have recently embarked on a consultation seeking views on the actions we need to take. Our health and care system is challenged by the changing needs of an ageing society and the consequential increase in people who experience multiple diseases. Our response in Wales to these changing needs has recently been outlined in our new long-term health strategy “A Healthier Wales” and there is now an urgent need to look carefully at the services we provide and the way in which they are delivered.

Chapter 2 serves as a reminder of the Prudent Healthcare Principles, which we have established as a cornerstone of our health and care services and looks at how these enduring principles can be delivered through the development of a value-driven approach to service design, delivery and evaluation. It provides some examples from across the Welsh healthcare system of prudent healthcare in action and points in particular to the need for a rethinking of our approach to the outcomes of healthcare. We need to reset our healthcare system by shifting attention from indicators of service outputs towards outcomes which really matter to people who receive services.

Given that change in our health system is inevitable, the role of knowledge and information takes centre stage and so, chapter 3 lays out the importance of our work in research and innovation. The proud tradition of health service research that began with the work of Archie Cochrane on lung diseases affecting mining communities in the Welsh Valleys, continues today through a network of research centres, units and support systems. Research is often overlooked, but it is vitally important to the economy of Wales; to the effectiveness and efficiency of health services; and to the sustainability of our NHS.

This year's report concludes with a consideration of some of the challenges which we face in the area of health protection; these can arise from infections and from environmental threats. We live in an inter-connected world and recent events, such as the rise in cases of measles across Europe, new and importable diseases such as Ebola and Monkeypox, and the use of chemical agents all serve to remind us that we ignore health protection arrangements at our peril. I will be looking further at ways in which we need to strengthen this aspect of our public health system.

Thank you for your interest in this report; I would welcome feedback on any of the issues that I have covered.

Dr Frank Atherton



Please feel free to
send feedback to;
Dr Frank Atherton

Chief Medical Officer for Wales
Directorate for Health Policy
Cathays Park, CF10 3NQ

03000 625039

Email: pschiefmedicalofficer@gov.wales

1. State of Our Health





Our changing population

The population of Wales continues to grow and in 2017 it was just over 3.13 million¹. It is expected to increase by around 4% over the next 20 years to approximately 3.25 million people² in 2037; with those aged 65 and over set to increase from 21% of our entire population to 27% (from approximately 643,000 in 2017 to 863,000 in 2037)³.

The number of those aged 75 and over is projected to increase by 58% between 2017 and 2037; increasing from 9% of the population to 14% by 2037 (from approximately 287,000 in 2017 to 452,000 in 2037)⁴.

The proportion of young people (those aged 0–15) in Wales is expected to decrease by the year 2037 and account for 17% of the overall population; down from 18% in 2017 (approximately 559,000 in 2017 down to 555,000 in 2037)⁵.

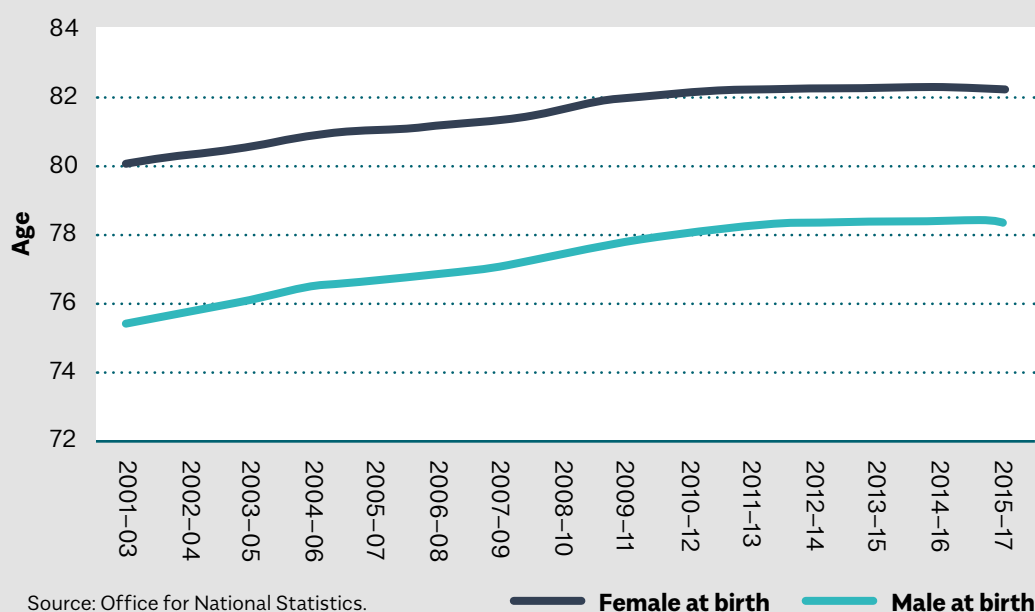
Living longer & living well

Statistics released by the Office for National Statistics (ONS) reveal overall life expectancy for the UK (at birth) in 2015–17 was 79.2 years for males and 82.9 years for females. In Wales, these figures are 78.3 years for males and 82.2 years for females.

Until 2011, life expectancy in Wales and the UK had been increasing for a number of decades; however, since 2010 the UK along with several other countries has seen a slowdown in these improvements in both male and female mortality. The latest figures for Wales showed a decrease of 0.1 years for both males and females, following a period with little change.

While this is a cause for concern and there remains controversy over the reasons, Public Health Wales (PHW), along with the ONS and Public Health England (PHE), are continuing to monitor ongoing trends in life expectancy and to explore the underlying factors.

Figure 1: Life expectancy at birth, Wales, 2001–2003 to 2015–2017





There remains a significant difference in life expectancy and healthy life expectancy between the most and least deprived areas in Wales; with an approximate eight-year gap in life expectancy and 18-year gap in healthy life expectancy⁶. We want people in Wales to live long and healthy lives and we've put in place a number of progressive policies to achieve that ambition. We also work closely with Public Health Wales to both monitor the ongoing pattern of life expectancy and to explore further the underlying factors.

A majority of adults report that they are in good general health, with 70% of over 16s reporting being in 'good' or 'very good' health⁷ in the National Survey for Wales 2017–18.

This figure varies across Wales, with the proportion of adults who reported being in good or very good health ranging from 67% in Cwm Taf Health Board to 76% in Powys Teaching Health Board⁸.

The burden of disease

The National Survey for Wales also highlighted that nearly half of adults in Wales report having a longstanding illness (with 21% reporting two or more illnesses). These figures rise with age and deprivation. In 2017/18, musculoskeletal disorders (17%) and heart and circulatory-related illnesses (13%) were the most commonly reported complaints⁹.

Overall, the percentage of adults being treated for at least one condition increased slowly between 2004 and 2015. Conditions in which there was some increase include diabetes and mental illness. Others (such as arthritis and heart conditions) showed a slight decrease¹⁰.

The early years

In historical terms, Wales' infant mortality rate (3.4 per 1,000) remains low¹¹.

Immunisation rates for children have risen over the past decade and most children in Wales are fully vaccinated. However, in 2017/18, 15% of children had not received all of their recommended routine vaccinations by their fourth birthday¹², meaning they were not fully protected from vaccine-preventable disease by the time they started school.

In 2016/17, the majority of children aged 4–5 in Wales were of a healthy weight. However, 27% of boys and girls were either overweight or obese¹³.

In 2017/18, National Survey for Wales results provided a number of markers of health-related lifestyle factors for children (aged 3–7), including:

87% ate fruit every day

68% ate vegetables every day

5% drank sugary soft drinks every day

65% were active every day¹⁴





Evidence suggests, by adopting the six steps to a healthier lifestyle, a person can reduce their risk of developing dementia by up to 60%.

Aging well

Wales has a higher proportion of older people than the rest of the UK, and therefore has a higher number of people suffering from chronic conditions and frailty. Our health service will need to take a co-ordinated, whole system approach to ensure that people of Wales receive the care and support they need as our population grows.

The number of people in receipt of residential services, and who are aged 65 and over, is also set to increase from 11,313 in 2015 to 29,161 by 2035¹⁵.

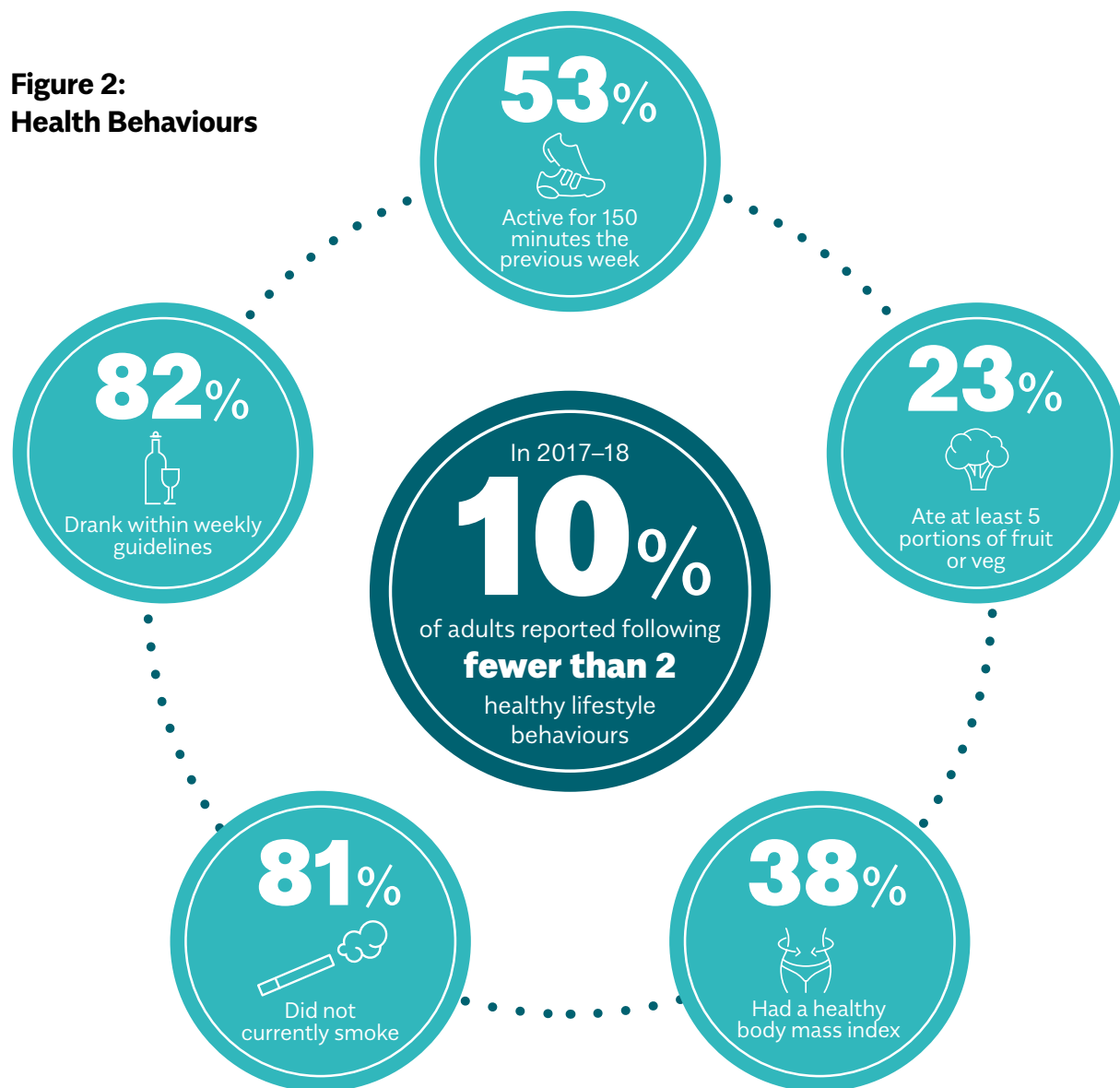
As recognised in the Welsh Government's national strategy *Prosperity for All*, remaining both mentally and physically active into old age may significantly reduce the risk of developing dementia, other health conditions, and depression as a result of loneliness and isolation.

However, with more people living longer, the number of dementia cases will continue to rise. Alongside dignified care for the individual, we also need to recognise the impact that dementia has on families, friends and carers.

Evidence suggests, by adopting the six steps to a healthier lifestyle, a person can reduce their risk of developing dementia by up to 60%¹⁶. Risk reduction and delaying onset will be a key theme within the dementia plan, which will look at support for dementia sufferers as a 'team around the family approach'.



Figure 2:
Health Behaviours



Health behaviours

The use of tobacco remains the leading single cause of premature death in Wales and a major contributor to health inequalities. Although smoking-attributable mortality has decreased in Wales, Public Health Wales estimate it is still accountable for over 5,000 deaths each year, around one in every six of all deaths in people aged 35 and over¹⁷.

Physical inactivity, diet and obesity levels are also significant burden of disease risk factors. With fruit and vegetable consumption declining (by 4 percentage points between 2008

and 2015) and the prevalence of overweight or obesity increasing (by 2 percentage points over the same period)¹⁸.

If this trend was to continue, it would result in three quarters of the population in Wales not eating the recommended levels of fruit and vegetables by 2025 and two thirds of the adult population in Wales being overweight or obese¹⁹. We are currently developing a healthy weight plan for Wales and expect to implement this from 2019.





Deprivation and health

Socio-economic status continues to influence our key health outcomes. Those in the least deprived areas of Wales are more likely to meet the guidelines around physical activity (59%) than those in the most deprived (42%)²⁰.

Similarly, in the least deprived areas we see greater adoption of guidelines around the consumption of fruit and vegetables (28%) than those in the most deprived (18%)²¹.

We see a similar effect on unhealthy behaviours, with those in the most deprived areas more than twice as likely to smoke (28%) than those in the least deprived (13%)²².

For alcohol consumption, we see that more people in the least deprived areas drink above the recommended guidelines (21%) than those in the most deprived areas (15%)²³. However, alcohol-related mortality rates are much higher in the most deprived fifth compared to the least deprived fifth of Wales, despite the opposite relationship for drinking above guidelines²⁴.

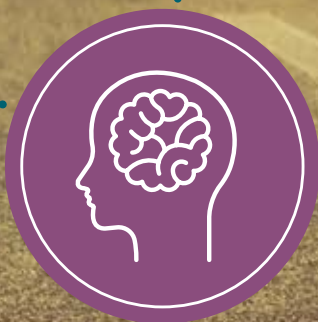
When looking at other health outcomes, we see the further impact of deprivation on children in Wales. Children are more likely to be born with a low birth weight in the most deprived areas of Wales (7.4%) compared with those in the least deprived (4%). This gap has widened between 2016 and 2017 from 6.9% and 3.3% respectively²⁵.

Almost half of children in the least deprived areas of Wales will be breastfeeding at 10 days (48.4%) while in the most deprived areas, this figure is just under a quarter (24.6%). Overall, the rate of breastfeeding in Wales has seen a slight increase between 2014 and 2017, with a greater increase in the most deprived areas²⁶.

Children in the most deprived areas are twice as likely (1.6%) to have decayed, missing or filled teeth (DMFT) than children in the least deprived areas (0.7%)²⁷.

Children are more likely to be born with a low birth weight in the most deprived areas of Wales

2. Prudent and Value Based Healthcare





Acting prudently and getting best outcomes = value

There has been considerable attention paid in the past few years to how health services will cope into the future, with the population growing increasingly older and having more complex health and care needs. This is something which the Parliamentary Review of Health and Social Care in Wales looked at in some detail in its report published last year²⁸. We simply cannot keep doing things in the same way, spending money in the same way and hoping for different results. We must focus the system on delivering the best results it can for people, within the available resources. As the Parliamentary Review report stated,

Whatever the overall envelope of funding, given current and future demands on the system, every pound spent must be more effective in improving outcomes for the users of service and for people of Wales²⁹.

Four years ago, the then Minister for Health and Social Services, and now First Minister of Wales, Professor Mark Drakeford endorsed the 'Principles of Prudent Healthcare' first described by the Bevan Commission, and set out his vision for how they could help deliver a more sustainable and person-centred health service. There was widespread agreement from within and outside Wales that these principles were important. My counterpart in Scotland, Dr Catherine Calderwood, has also published two reports on the 'realistic medicine' concept which shares many similarities with prudent healthcare and 'rethinking medicine' has appeared as a similar emerging approach in the NHS in

England. Our prudent healthcare principles have continued to be supported in Wales, including in last year's report from the independent Parliamentary Review panel and then in A Healthier Wales: Our Plan for Health and Social Care³⁰.

Given the continued support for the prudent healthcare philosophy in these strategic documents, it seems timely now to consider how these principles have been, and are being, refined and how they are becoming embedded in the health service in Wales.

It can be difficult to measure the extent to which the prudent healthcare concept has been adopted in the NHS in Wales. We think there is significant professional awareness of prudent healthcare although there may be barriers in relation to its consistent implementation³¹. Prudent healthcare is ultimately about clinical culture and decision making in co-production with the public. It provides a new lens through which we can understand and seek to improve the excellence of the care we offer. Choosing Wisely Wales is one example, based on the international movement in which professional bodies advise on unnecessary care, working to ensure professional engagement in shared decision making, a focus that should directly involve those accessing services and which needs to be main-streamed in all NHS organisations at pace. Our programme eventually became known as Making Choices Together, to reflect the changing role of doctors to become supporters or mentors for their patients in collaborative decision making.



Building and harnessing value based approaches

The application of 'value based healthcare' is increasingly being seen in Wales as a way of delivering the prudent healthcare principles in a measurable way. It requires a healthcare system to become truly data-driven in order to improve clinical outcomes and inform the allocation of resources for the greatest positive impact on individuals and the people of Wales.

Value based healthcare is an internationally recognised approach to delivering the best outcomes for people by providing the right care for them as individuals³². It presents an exciting opportunity, if we choose to grasp it, to deliver and measure prudent healthcare and therefore secure sustainable services. High value does not have to mean high cost, indeed simple things done consistently often provide the highest value, so value based healthcare approaches may actually be the simpler ways of achieving the same outcomes, built around the hopes and wishes of each person affected. This, at its heart, is prudent healthcare.

A number of tools have been rapidly put in place to build and harness value in the system. NHS Wales organisations have been working with the International Collaboration for Health Outcome Measurement (ICHOM) to build knowledge and capacity in this area. This strategic alliance has supported our health boards to collect and report outcome data for a range of medical conditions areas, including lung cancer, heart failure and cataract.

In addition, following work in England, we have strengthened our focus on unwarranted variation in services and outcomes to reveal the under and over-use of different aspects of healthcare.

This is allowing the targeting and removal of low value interventions and the re-investment of resources in higher value interventions. One example of this approach is our Respiratory Health Delivery Plan for 2018–2020 which describes significant variation in many aspects of respiratory care and explicitly seeks to drive investment towards the higher value, often lower cost, interventions. There is evidence in Wales of disproportionate spend on 'triple' bronchodilator therapy, relatively expensive but low in value, in comparison with less expensive but higher value interventions such as flu vaccination in higher risk groups, smoking cessation with pharmacotherapy and pulmonary rehabilitation, so the group is leading work to redress this imbalance.

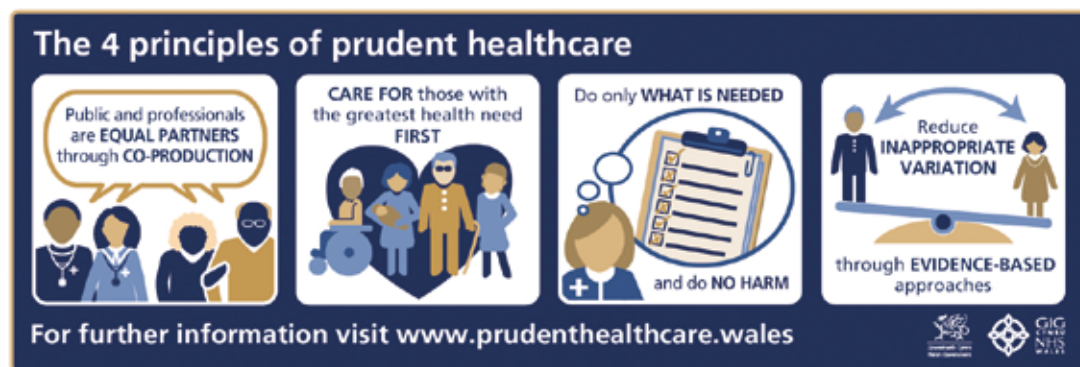


Case study

Using Patient Reported Outcome and Experience Measures in memory services (PROMs and PREMs)

By using PROMs, PREMs and activity based costing methodology Aneurin Bevan University Health Board identified that there was variation and inequality in the memory assessment service across different areas on its patch. The outcome measures and costing data were combined and identified one pathway which offers better outcomes at a lower cost. The pathway is currently being implemented across the organisation which will ensure all patients receive the same standard of care.

**Figure 3:
Principles
of prudent
healthcare**



There is also a national programme in place to collect consistently Patient Reported Outcome and Experience Measures (PROMs and PREMs), the capture of this information being crucial to understanding the true value of a healthcare intervention from the individual's point of view. The introduction of PROMs into orthopaedic care in the Cardiff and Vale University Health Board has reduced the need for low value follow up appointments by as much as 70%. Work is now needed to bring together these various means of outcome data collection into our National Data Resource.

A reminder of the prudent healthcare principles through the lens of value

Prudent healthcare describes the need for an altered relationship between the public and professionals, working together in a more equal way to improve the health of the Welsh population. The principles are:

For the public and professionals to be regarded as equal partners through co-production and shared decision-making.

To prioritise those in greatest need.

To aim to meet people's health goals in the least invasive way possible in order to improve outcomes and minimise harm.

To use evidence to reduce unwarranted variation in care across Wales to ensure fairness, improved outcomes and the reduction of waste.

If these prudent healthcare principles are applied, then there will be situations when more care is provided to achieve a greater benefit, while at the same time, there will be other situations in which less care can be beneficial. A number of published articles

have described how 'over treatment' exists and is often harmful. Many people may be surprised that healthcare can be harmful, but in truth, there is a wide range of possible outcomes for individuals from much of the care we provide to populations. It is therefore not always better to receive more healthcare, although sometimes this may be needed, depending on the needs and wishes of the individual. Through placing greater value on patient outcomes rather than the volume of activity and the complexity and sophistication of procedures delivered, prudent healthcare aims to rebalance the NHS and create a more patient-centred system.

As an example of potentially harmful healthcare, it may be helpful to consider the use of multiple medication in a frail, elderly person. Such a person will often have a number of conditions that can be treated medically but when this results in a very long list of potent drugs, the overall impact can be more harmful than it is helpful. The evidence is strong that many hospital admissions in frail, elderly people happen because of the effects of their medication. This is not a good outcome from the care provided and not a prudent use of the always limited healthcare resources.

This relationship between the outcome for the patient and the cost of care is now known as the value of healthcare. This concept is proving to be a helpful approach to understanding, implementing and measuring prudent healthcare. Generally we would wish to deliver the highest value healthcare to achieve the best possible outcomes in the most individually appropriate and affordable ways and to avoid low value care, even that which is expensive and technologically sophisticated, that will result in no benefit or even harm.



Continuous improvement

is a basic responsibility for everyone involved in the provision of healthcare

How prudent healthcare principles can improve the value of healthcare

Prudent healthcare has undoubtedly provided a strong and recognisable foundation for how we must improve healthcare in Wales. There have been a number of excellent actions and initiatives, some of which I highlight in this report, but, as mentioned above, we are as yet to harness fully the principles and embed them as business as usual.

Continuous improvement is a basic responsibility for everyone involved in the provision of healthcare; we are also all responsible for ensuring the best possible use of the monies made available to the NHS. A focus on value based healthcare can help us deliver on these responsibilities and provide evidence of the progress being made in many parts of the NHS in Wales. As a starting point, it might therefore be helpful to express the prudent healthcare principles through the language of the value of care, as below.

Public and professionals as equal partners through co-production

This first prudent healthcare principle is crucial to the delivery of modern healthcare services and for improving the experience and outcomes of the people using those services. Here is a definition of coproduction from the Social Care Institute for Excellence:

A way of working whereby citizens and decision makers, or people who use services, family carers and service providers work together to create a decision or service which works for them all³³.

For this principle to be applied successfully we must consider to what extent people are (and feel) involved in caring for their health. There is evidence that when people feel more involved and informed about the options of care available to them, and are able to make their own decisions, their personal outcomes from care are markedly better.

At an individual level this means that we must ensure that public and professionals are equal partners in the consultation when making decisions. This requires a shared understanding of all the treatment options if we are to support people in achieving their health goals in a way that makes sense for them in the circumstances of their own lives.

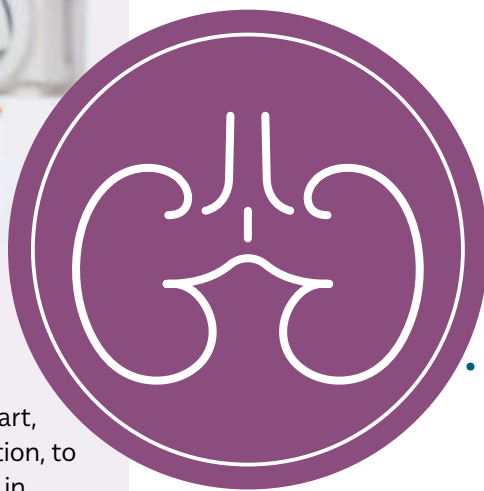
Doing this well requires time, often taken over multiple consultations, and might well utilise the differing skill sets of a multidisciplinary team. This should include not only discussions about specialist referrals, drugs, radiotherapy or surgical interventions and their relative merits, but also when / if to have a scan, or even to take holidays or any other activity important to that person. This is all part of supporting the decision making process of each individual patient. Not only will a co-productive approach improve individual clinical outcomes, but also it is likely to reduce waste as the evidence is that people tend to be more conservative in their preferred treatment options than professionals might expect, often resulting in a 'de-escalation' of care towards more simple and timely pathways.



Case study

Co-production in kidney care

The Welsh Renal Clinical Network, on which patient representatives and NHS professionals play an equal part, decided that it wanted to drive out inappropriate variation, to disinvest in things which do not work well and reinvest in care and treatment which meets the needs of individuals. This has been achieved by making bold decisions, but, crucially, ones guided by those working within the system and receiving care. One example is in the case of kidney transplantation, in which Wales is a UK leader. By investing in renal pharmacy teams which could exercise better control over types and costs of medication, NHS Wales is delivering millions of pounds of recurrent cost saving from drug budgets. This money has been invested back into the service allowing more people to receive a successful transplant. It funds extra specialist nurses to put more patients in the system to be worked-up for transplant (and taken off dialysis). It funds specialist pharmacist prescribers and renal pharmacy teams to manage the complex, lifelong anti-rejection therapies. This Welsh model is self-funding and sustainable for the long-term. Patients were fully involved in the heart of the service redesign and their requirements in relation to support, contact and access to services closer to home. As a result this cohort of patients has developed the health literacy needed to be equal partners in their own care. This is an excellent example of prudent healthcare delivering real value for patients.



There is evidence that when people feel more involved and informed about the options of care available to them, and are able to make their own decisions, their personal outcomes from care are markedly better.



43,000

children (under 16)
received care in
Community Dental
Services (CDS)

Care for those with the greatest health care need first

This principle steers us towards promoting equity in health outcomes by matching the response of the healthcare system to the level of need of the individual. Equity may be defined as the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically.

For some individuals their need may require a rapid response, and for some people, their level of need may require more, or more complex, interventions than needed by others. As with the first principle, the second drives us towards a more individualised response from the healthcare system than is often currently provided. A 'one size fits all' approach may appear on the face of it to be equal, but in fact it can let down those at greatest risk, and does not result in consistency of good outcomes for all, as many will need either more or less than the standard approach. One such example is when all referrals from primary care are placed on the same waiting list for treatment, whatever their level of need.



Case study

Tackling inequality in dental health

The NHS primary care contract for dentists in Wales is being modified in a collaborative contract reform programme to support dental teams in Wales to adopt a prudent healthcare approach to dental care delivery in practice. The current contract is focussed on treatment activity and does not incentivise prevention, expanding the use of skill mix or welcoming new patients. Improvements are beginning to be seen in population level access improvement for children.

The latest access figures demonstrate a steady and sustained improvement in child access to NHS dental care. In addition to children accessing their family dentist in the same period 43,000 children (under 16) received care in Community Dental Services (CDS). It is possible that some children are seen by both family dentists and the CDS in a shared care arrangement, but this number is likely to be small. At the centre of the reform approach is supporting dental practices to use the skills of the whole team to better meet patient need, step up prevention and focus on outcome measurement in oral health. The change means that released dentists' time can be used to open access to preventive dental care and also to better meet the needs of those patients with disease and advise those at greatest risk, with less time being spent on recalls for the lowest need and risk patients.

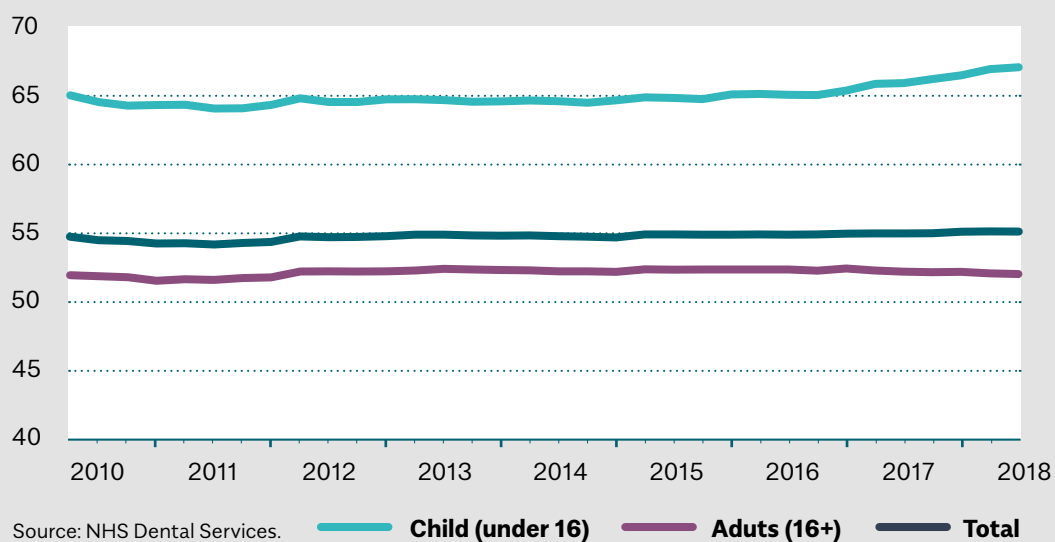
This example shows how systems develop over the years to the point that they are no longer serving patients well. Healthcare professionals can see the problems in the system and feel frustrated by them, but are not always empowered to make change. Government, patients and professionals, working together can use the tools at their disposal to uncover inequalities and negotiate changes.



By deploying healthcare resources towards those with the greatest need, and who are likely to derive the greatest benefit from treatments, the value of the healthcare offered is maximised.

Underproviding for those with the greatest risk is likely to result in less good outcomes, while overproviding for those with low risk represents unnecessarily expensive and low value healthcare.

Figure 4: Percentage of the Welsh population treated in the 24 month period by quarter and age group





Do only what is needed and do no harm

We know that healthcare, whether medical or surgical, changes people's bodies and therefore always comes with risk and the potential for harm. We have to work carefully to make sure that the risks and benefits of any intervention in any individual are carefully considered and understood.

Delivering healthcare always demands a balance between risks and benefits. We have developed many evidence-based guidelines for care but there are inherent problems with applying single disease guidelines to people with complex needs, yet those with more complex needs are generally not included in the clinical trials that have provided the evidence. There is always a risk of harm when we take any action so we should truly ascertain our patients' health goals and seek the least invasive way to achieve them. In so doing we will reduce harm and improve outcomes, whilst still practising evidence-based medicine, albeit balanced with each individual's needs and wishes. The goals and the solutions to reach those goals must be arrived at together having considered the best available evidence.

We have to work carefully to make sure that the risks and benefits of any intervention in any individual are carefully considered and understood.



Harm caused by healthcare (iatrogenic harm) is both visible and invisible. Serious adverse drug reactions, hospital-acquired infections, surgical complications and medical errors are relatively easy to identify. Less visible harms might include the effects of being on more than four medications, multiple medical tests or indeed any treatment which in itself may be more burdensome for the individual than the disease being treated. One unfortunately very common example of invisible harm from healthcare is the loss of mobility and independence that occurs during the hospitalisation of many frail or elderly patients.

Harmful healthcare is clearly low value healthcare, particularly when the likely benefit of treatment was low to start with. Harm is not only a very poor outcome, but also can be expensive to deal with, perhaps as shown by the cost of more complex social care which may be needed by the frail, elderly person who is immobile when leaving hospital. We need to become better at recognising and preventing avoidable harm from the care we provide. Collaboration between patients, their families and the health and social care system will be needed to remodel our care options to support the safest care and best outcomes.



Reduce inappropriate variation

Unwarranted variation is a term coined by Dr John Wennberg, founder of the Centre for Evaluative Clinical Services at Dartmouth Medical School in the United States. He defined it as variation in healthcare delivery that cannot be explained by illness, medical need or evidence. This definition needs to be revisited because we have already described how outcomes can be improved by more individualised decision making. This could result in some variation at a local level highlighting the distinction between appropriate and inappropriate variation.

Inappropriate variation may be seen as substantial differences in operation or intervention rates between similar populations served by different healthcare providers. Such regional variations are likely to be inappropriate and indicative of wide variations in the value of the healthcare

being provided in different areas. One such example we have seen is of widely different rates of tonsillectomy within Wales. Looking at this sort of variation is a useful means of helping clinical teams reflect on their practice and why they take the approaches they do, and if in fact they are delivering the best outcomes and value for their populations. The measurement of variation is certainly not new, but we understand more than before how clinical attitudes and behaviours will determine the changes that follow when the data are shared.





How do we improve the 'value' of care in Wales?

The OECD in its review of quality across the UK healthcare systems published in January 2017³⁴ stated that quality is at the heart of the Welsh health system and it is certainly the case that there is a genuine commitment to improvement across the organisations in Wales. Following the 1,000 Lives campaign in 2008–10, NHS Wales has retained a central quality improvement support team to review international evidence and bring expertise in data analysis and quality improvement methodology to collaborative working with our health boards and trusts. There are several examples to show the success of this approach including improved survival rates for patients with sepsis and reduced rates of health care acquired infections and ventilator associated pneumonias. Such examples in which the outcome improves and the cost of harm decreases are clear instances of improvement in value. The 1,000 Lives team now is actively planning how to scale up quality improvement further to improve value.

Each organisation must have continuous quality improvement embedded in its culture. To support this, Welsh Government is bringing forward a strengthened Duty of Quality in a forthcoming Bill which will be laid before the Assembly. In the meantime, there are many excellent examples of efforts to improve healthcare value across Wales.

Our commitment to improve value based healthcare is described within the recently published national plan A Healthier Wales. In support of this plan we are working with a range of partners within and outside the UK to improve our ability to measure and record improvements in value. To improve our ability to measure individual clinical outcomes, we have developed strong links with ICHOM and our colleagues within NHS Wales Informatics Services (NWIS) have developed a national IT platform to enable measurement of Patient Reported Outcome and Experience Measures (PROMs and PREMs).

Each organisation must have continuous quality improvement embedded in its culture.





Case study

Reducing variation in maternity care

The Obstetric Bleeding Strategy for Wales (OBS Cymru) is an All Wales quality improvement project with the aim to reduce variation in care and reduce morbidity and mortality associated with post-partum haemorrhage (PPH). If heavy bleeding occurs it is important that it is treated quickly so that a minor haemorrhage doesn't become a life-threatening event. PPH is recognised as the leading cause of women needing extra care and support following childbirth with 1 in 10 women experiencing blood loss in excess of 1 litre, and in 1 in 200 life threatening bleeding can occur. It seeks to do this by using four key principles;

Risk assessment.

Measured blood loss to accurately identify those women with excess bleeding

Multi-disciplinary team working

Bedside testing of blood clotting

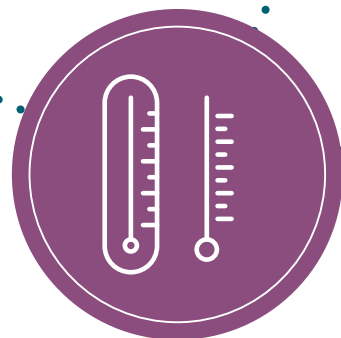
Using these four principles helps identify those women who may require further intervention to control the bleeding, be that surgically or via use of blood products. It can also quickly identify those women who don't require blood products, thus reducing avoidable harm. As this is an All Wales approach, it has reduced inappropriate variation and initial promising data shows a reduction in the number of women exposed to blood products as well as reduction in admissions to critical care.

To develop a better understanding of the cost of healthcare, NHS Wales Finance Directors are implementing new approaches including activity based costing which helps measure the cost of all clinical activity along a care pathway and also programme-based budgeting which measures the cost of all care provided to groups of patients with particular conditions in primary care and hospitals. We have seen that clinical teams are keen to be engaged in discussions about improvement when provided with clear evidence of variations in value, which are exposed, often for the first time, by these processes.

The principles of value based healthcare are being systematically applied to the issue of procurement in Wales. This involves collaborative working between the Evidence Based Procurement Board and Health Technology Wales to produce position statements to guide the procurement of a range of items including anti-microbial dressings, capsule endoscopy and hip replacements. Work is ongoing to establish effective industry relationship to underpin a value based approach to enhanced recovery after surgery and the use of spinal nerve stimulation for faecal incontinence.

PPH

is recognised as the leading cause of women needing extra care and support following childbirth



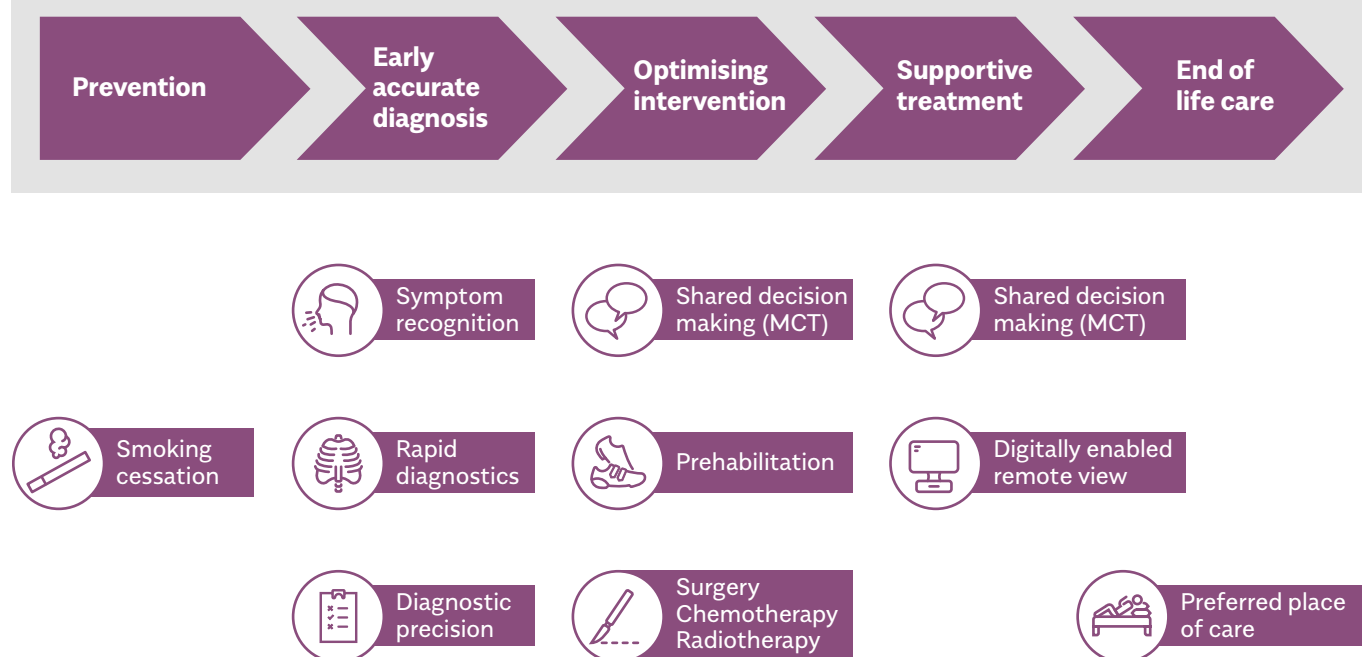
What's next for Prudent and Value Based Healthcare in Wales?

There is clearly a huge amount of enthusiasm within Wales to realise the potential offered by prudent and value based healthcare and whilst much good work has been done, we must now make a concerted effort to systemise the approach across all organisations and care pathways. This is likely to take the form of both building local capacity and putting in place some central support, particularly in the development of data capture and analysis. The Minister for Health and Social Services has agreed to invest £500,000 per annum in the development of value based healthcare approaches and this very welcome sum of money must now be used to make a step change in the programme. Dr Sally Lewis,

a GP from the Aneurin Bevan Health Board area has been appointed as clinical lead for value based healthcare. Dr Lewis has already made great progress in building consensus around Wales and has brought together leads for value based healthcare from all our NHS organisations. A number of key areas for our future effort have been identified including a focus on better collection of data and higher quality information.

Initially work is being concentrated on areas where there is already good information and patient reported outcomes, for example in lung cancer and heart failure (figures 5³⁵ and 6³⁶). This will lead to the production of dashboards to allow a focus on where the value lies in the care pathway, and what is not working so well.

Figure 5: Improving outcomes, improving values in lung cancer³⁵



Source: Welsh Government: Value Based Healthcare

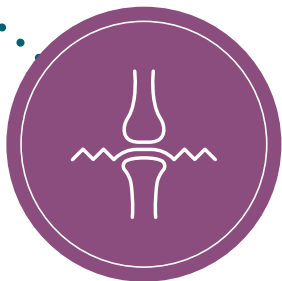


Figure 6: What data do we have?³⁶

Aim	Prevention	Early diagnosis	Optimise treatment	End of life care
Data type				
Atlas of variation measures Eg 30 day readmission rate	😊	😊	😊	
Spend and outcome tool (SPOT)	😊	😊	😊	
Costing data		😊	😊	
Process variation data Eg time to CT, time to echo		😊	😊	
Service variation (spend/outcome) Eg prehabilitation, CNS models	😊	😊	😊	
Patient and clinically reported outcome data (inc Patient experience)		😊	😊	😊

Source: Welsh Government: Value Based Healthcare

However, the information we have for these conditions is not necessarily replicated in other clinical areas. In order to change the Welsh NHS into a value based healthcare system it will be necessary to build the infrastructure to capture data and turn it into useful information which meets the needs of decision-makers at all levels and in all contexts.

This is intrinsically linked to digital transformation towards flexible, patient-led access to healthcare and their records. Data collection in the NHS should also happen as an integral part of routine care if we are to ensure robust and complete data capture, and not to create a burden of measurement for patients and clinical teams. The national PROMs, PREMs and Clinical Effectiveness programme contains some elements of functionality necessary to support this work going forward. Most Boards are also now developing the capacity to project manage the implementation

of outcomes measurement in-house, though this work is at varying stages of maturity and is not always incorporated into the overall value-based healthcare approach in the organisation.

What is now needed is a concerted effort to systemise the pockets of good practice which are already happening across Wales.



Recommendations

Infrastructure

1. Health boards should be challenged to set out their approach to value based healthcare in their organisational plans (IMTPs) and other strategic documents. This should become central to performance and quality discussions between NHS Wales organisations and the Welsh Government.
2. The fledgling value-based healthcare teams which have been set up across Wales should be given formal support by NHS boards and tasked with developing a vision and action plans for their organisations, with key milestones.
3. A suite of data sets showing variation in health care services should replace our current condition specific delivery plans and NHS implementation groups should use these to develop new national improvement plans.

Data

4. There should be a step change in efforts to measure and use patient outcome data at all parts of the system, focusing on enabling the best possible communication with patients leading to more flexible models of healthcare.
5. New costing models that enable measurement of value and variation in value should be used more consistently across NHS Wales organisations.
6. There should be a relentless drive towards a data-driven system that allows healthcare organisations to focus attention on areas in which to invest for the greatest impact on outcomes.
7. Various outcome measurements modalities and platforms should be integrated into the National Data Resource.

Good practice

8. There should be more direct sharing of our experiences and learning from others. Consideration should be given to holding joint workshops with colleagues in Scotland to compare our respective approaches, as there are many similar challenges and opportunities to consider.
9. A repository of good practice should be developed which will make the concept of value real and understood across health and care.
10. Prudent Healthcare principles should guide the development of a National Clinical Plan for Wales.

Communication

11. Consideration should be given as to how the concept of value should be communicated to the wider professional community and the public and how their support for it can be harnessed.
12. Regular updates on prudent, value based healthcare should be provided by the Welsh Government.



3. Valuing Research

Without research
there wouldn't
be treatments like

IVF



38%

of adults think all trials
involve testing
a new drug

What is research and why do we do it?

In the NHS, over the last 70 years, research has given us things that we might take for granted today but they all started out as ideas. Through diligent testing we now have solid evidence that they work – or in some cases cause us harm. Without research there wouldn't be treatments like IVF or devices such as pacemakers – and we certainly wouldn't know that smoking causes cancer.

Health and social care research is about finding new knowledge that could lead to changes in treatments, policies or care. Quite often, taking part in research only takes a few minutes – like filling in a questionnaire at your GP's surgery; giving permission to researchers to look at medical notes; or maybe giving a blood sample.

According to figures from the National Institute for Health Research, 38% of adults think all trials involve testing a new drug while 27% believe trials only take place in hospitals³⁷.

As a country, we in Wales have a rich heritage of research excellence. Back when the NHS was established in 1948, more than 200,000 men worked gruelling, dirty and dangerous shifts in Welsh coal mines³⁸. Over 22,000 struggled with the lung disease pneumoconiosis, or 'black lung', with 85% of those living and working in South Wales³⁹.

It was this disease that Archie Cochrane, a doctor at Llandough Hospital in Penarth, tackled head-on with an ambitious study of entire mining communities in the Rhondda Fach and Aberdare valleys. On a scale never before seen, chest x-rays and detailed health surveys were performed to see whether a particularly crippling form of lung disease – progressive massive fibrosis – was caused by a combination of black lung and tuberculosis.

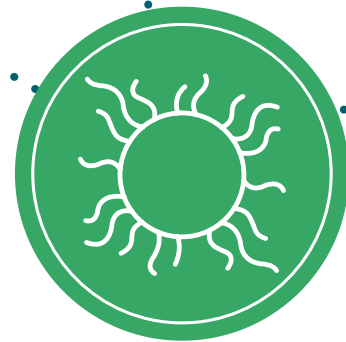
All of this is research.

Figure 7: What is research?



Source: Health and Care Research Wales' animated video 'What is research?'

The Welsh Government recognises the critical role research has to play in discovering new treatments, preventing ill health services for patients and the public.



They found out much more than that, linking coal dust with a range of disabilities and ill health amongst these communities. An astonishing 95% of the community – some 25,000 people – agreed to take part thanks to the highly organised, intensive work of a field team of medics, nurses and disabled miners using ground-breaking methods.

Building on this heritage the Welsh Government recognises the critical role research has to play in discovering new treatments, preventing ill health and improving health services for patients and the public. Through Health and Care Research Wales, the Welsh Government funds an excellent and diverse research infrastructure, focussed on developing high quality research that positively impacts on the health, wellbeing and prosperity of people in Wales.

The infrastructure comprises 5 research centres, 3 research units, 3 clinical trials units, and 3 support groups.

The centres and units cover a diverse range of research, including mental health, primary and unscheduled care, population health and wellbeing, cancer, ageing and dementia, neurodegenerative diseases, diabetes and kidney research. They have a remit to increase the number of high quality research studies conducted in Wales by applying for external grant funding. They are also expected to publish their work in recognised scientific journals, build research capacity in their field and work with NHS and social care partners to ensure that research outputs are translated into meaningful, 'real-world' benefits for patients.

Infrastructure Support Groups and Clinical Trials Units are critical components of the research development infrastructure, providing expertise, opportunities for

collaboration and underpinning support to the Centres and Units and the wider research community in Wales. There are three Infrastructure Support Groups, providing expertise in data linkage, genetics and genomics and health economics. Clinical Trials Units provide expertise in clinical trials and other well-designed studies, which is vital to ensure they are of high quality, successful, conducted in a timely manner and meet regulatory and governance requirements.

Health and Care Research Wales the Welsh Government also sustains the Support and Delivery infrastructure consisting of NHS R&D services and the Health and Care Research Wales Support and Delivery Centre.

Health and Care Research Wales NHS R&D services are based at each NHS organisation in Wales, they build local capacity and capability to support high quality research to maximise impact.

The local services are delivered by NHS R&D Departments who employ R&D managers/coordinators to facilitate the sponsoring and/or hosting of studies.

The Health and Care Research Wales Support and Delivery Centre is a Wales-wide service, providing centralised support functions across Health and Care Research Wales and also on behalf of NHS R&D services. The Support and Delivery Centre provides the coordinated support for a suite of delivery programmes and projects.

Health and Care Research Wales Support and Delivery Figures⁴¹



14,769

participants recruited to
high quality research
studies in the NHS

245

commercial feasibility
requests sent
to potential
investigators



42%

of studies open in more
than one site in Wales

124

commercially sponsored
studies open and
recruiting in
the NHS

386

high quality research
studies open and
recruiting in
the NHS



1,143

participants recruited
into commercially
sponsored studies
in the NHS

118

GP practices involved
in the Primary Care
Research Incentive
Scheme (PiCRIS)



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Research improving outcomes

Research makes a real difference to patients. Evidence⁴⁰ shows that patients in clinical trials have a higher survival rate than those not in trials, even if they are in the control arm – meaning they do not receive the intervention. It has also been shown that hospitals who actively carry out research have better outcomes than those hospitals that don't do research.

In Wales we are working to ensure that patients can access research trials no matter what their condition, or where they are located. Recruitment into studies is increasing, and changes to our national activity based funding policy are encouraging a focus on the support and delivery of high quality research in the NHS. This is increasing opportunities for the population of Wales to participate in studies that will make a real difference

Research makes
a real difference
to patients



Case study

Wales' pivotal role in world's largest clinical trial

The Wales Cancer Bank, the nation's facility for storing blood and tissue samples from cancer patients for use in research, has a crucial role in the world's largest clinical trial. That trial, 'Add-Aspirin' is testing whether a simple daily dose of aspirin could stop a wide range of cancers from recurring after treatment. It draws on the Bank's world-leading large-scale international trial expertise.

It is one of only two UK biobanks involved in research in this area, receiving samples from participants affected by common cancers including early-stage breast, oesophagus, stomach, prostate and bowel since 2015.

Part of the Wales Cancer Research Centre, funded by Health and Care Research Wales, the Bank's involvement goes beyond understanding aspirin's potential and spotting any side effects. It has stored samples from over 100 different centres in the UK which are available for future research studies aimed at preventing and killing cancer, a disease that attacks a new person every two minutes.

Dr Fay Cafferty from the MRC CTU said: "The Wales Cancer Bank was selected ...due to their extensive previous experience and successful work on large-scale, international, multi-centre clinical trials, as well as in routine sample collections, including a number of productive collaborations with the Medical Research Council, Velindre's Clinical Trials Unit and Cancer Research UK."

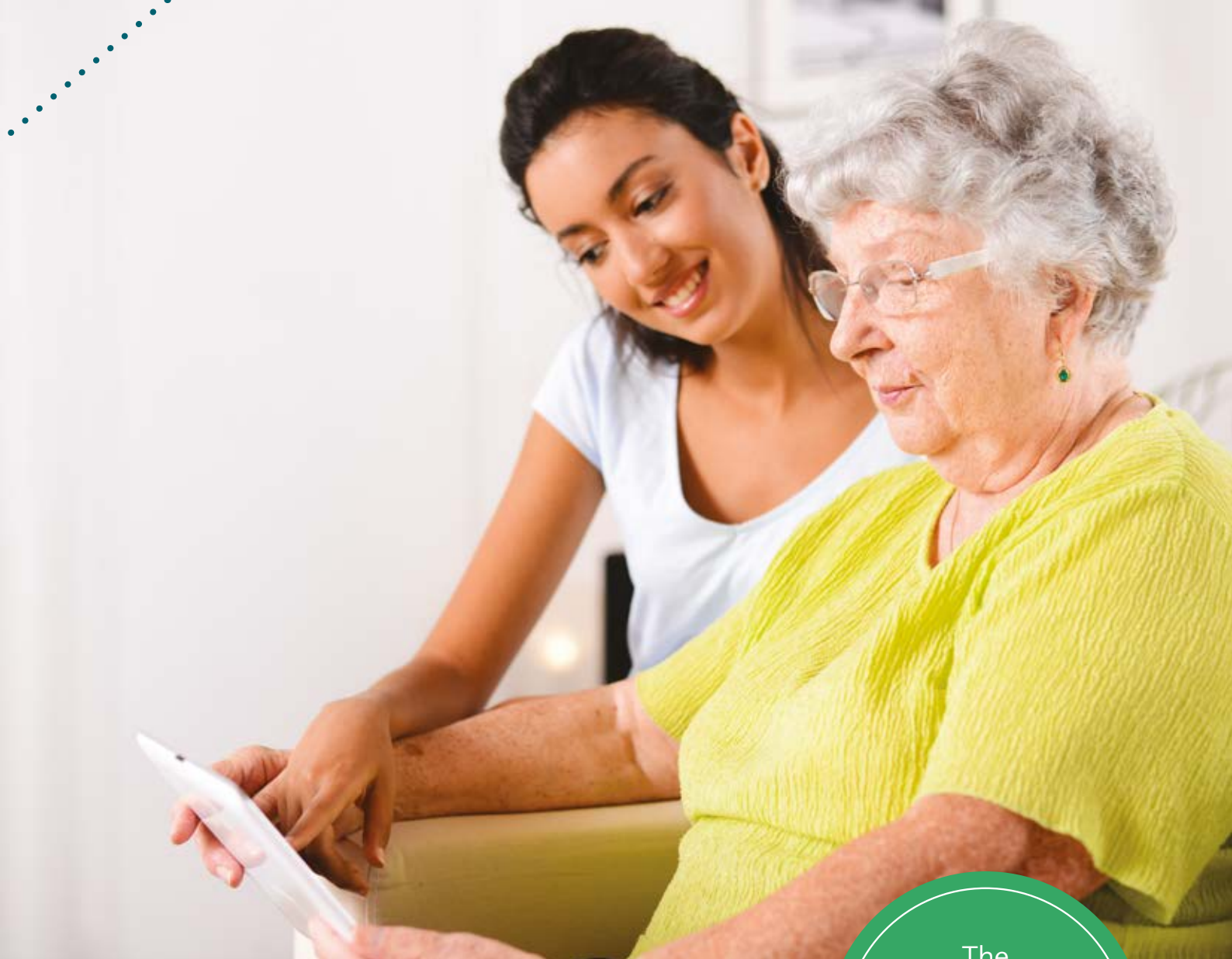
Welsh people are also playing their part in the study, with participants joining Add-Aspirin at centres across Wales contributing to the target of 11,000 participants. Jayne Lambe joined the trial after her diagnosis and treatment in 2016.

"I'm taking part in the study because I don't want anyone else to go through what I have – it's the most horrendous thing you can ever be told. If this is helping anybody in any way, it's worth it."

Having recently lost her father, Jayne experienced denial on diagnosis thinking her symptoms were tied up in her grief, but following treatment she is now in remission and joins thousands of other participants in taking one pill a day.

That pill may contain one of two doses of aspirin, or no dose at all (placebo), with neither Jayne nor her doctor knowing so that any feel-good, 'placebo' effect from simply taking a pill is accounted for. Jayne is now a year into the five year participation period, and will be monitored at routine follow up appointments with her doctor like all the other people involved.

Those centres include University Hospital of Wales in Cardiff, Wrexham Maelor Hospital and Glangwili General Hospital. It will be some time after the trial stops recruiting in 2021 that the results will be known, but the potential for an inexpensive and simple way of preventing cancer returning is exciting.



Doeth am lechyd
Cymru

HealthWise
Wales

HealthWise Wales

Wales currently faces many health challenges and with an ageing population, one in three adults say a health problem affects their day-to-day activities.

HealthWise Wales is Wales' national project to better understand and improve our health and care. It aims to collect detailed health and lifestyle data from as many people in Wales as possible to inform new treatments, health policy and NHS and social care services long into the future. With more than 25,000 people across Wales already registered we also view it as a window into

research for the public. HealthWise Wales provides a means of engaging with the public about Wales' health and social care research, and involving them in its design and conduct.

It's the largest research study of its kind in Europe, collecting the information needed to better prevent and treat long term health conditions such as heart disease, diabetes and dementia.

Core to the project's aims is prioritising research questions and the creation of research ideas in partnership with the public.

The
LARGEST
research study of
its kind in Europe

182

jobs supported by
Health and Care
Research Wales'

Research and the contribution to health and wealth

High quality health research is not only important for improving patient outcomes but also has a valuable economic role to play; generating income and creating (and safeguarding) high-value jobs.

Since the infrastructure groups were established in April 2015, researchers based at Health and Care Research Wales Centres, Units, Infrastructure Support Groups and Clinical Trials Units have collectively reported they have led on 532 successful grant awards, bringing more than £139m research funding into Wales, and supporting more than 58 high quality jobs (in addition to the 182 jobs supported by Health and Care Research Wales' direct funding of the research infrastructure). Additionally, researchers have reported that they have published over 2386 new research articles, collected over 49,455 new tissue samples and issued more than 15,227 samples to support translational research projects in Wales and beyond⁴².

Health and Care Research Wales Clinical Research Infrastructure outputs from 2015–2018

532

successful grants
awards

£139m

research funding
into Wales

Supporting
more than

58

high quality jobs

Published over

2386

new research articles

Collected over

49,455

new tissue
samples

Issued more than

15,227

samples to support
translational research
projects in Wales
and beyond

Case study

Impact of commercial research

Abertawe Bro Morgannwg University Health Board completed a study to compare the outcomes of a standard treatment with or without the addition of an immunotherapy treatment in patients with relapsed or refractory multiple myeloma (a type of blood cancer). The study was sponsored by a biotechnology company, and coordinated by the National Institute for Health Research (NIHR) feasibility service. It aimed to establish whether the addition of immunotherapy would benefit patients, through being more efficient, prolonging survival and improving quality of life. Patients in the study continued to receive treatment as long as they benefited from the study drugs and did not suffer severe side effects. Singleton Hospital was one of eight sites in the UK and recruited six patients in total. Three patients continued to receive treatment as a result of the study and have received better treatment options as a result.

Working collaboratively to ensure value in research

We continue to work with partners to increase the value of health and social care related research and to create funding opportunities for Wales-based researchers.

Ensuring Value in Research – an international effort

Through Health and Care Research Wales we are proud to be a member of the Ensuring Value in Research (EViR) Funders Collaboration and Development Forum. Co-convened by the National Institute for Health Research (England), the Patient Centered Outcomes Research Institute (USA), and ZonMW (Netherlands), the Forum brings together research funders, and others, in a dedicated, collaborative, international effort to advance research funding practice, reduce waste and increase the value we get from the research that we fund.

The work of the Forum gained considerable momentum in 2017–18, with meetings in Den Haag and Washington DC leading to the agreement of a consensus statement, a set of guiding principles, a Lancet article and the creation of the EViR website.

“While agreeing a consensus statement and set of principles does not in itself add value to research, we see it as a precursor to action at both individual and collective levels. In some cases we know what kind

of action is needed and the challenge is a practical one. In other cases matters are less obvious. Either way, the Forum allows the exchange of ideas and the sharing of good practice among organisations who have a real will to advance practice and effect real change.” Michael Bowdery, Head of Programmes and Joint Interim Director at Health and Care Research Wales

Creating funding opportunities

In keeping with our long term strategy we continue to work with partners to create funding opportunities for Wales-based researchers.

In 2017–18, the launch of UK Prevention Research Partnership (UKPRP) funding calls resulted in a Welsh led network progressing to full-application stage. If successful this could lead to further Welsh involvement in other networks and developing consortia.

We continue to work with a range of funding partners, including the Medical Research Council (MRC), the Economic and Social Research Council, the Engineering and Physical Sciences Research Council, the British Heart Foundation, the Wellcome Trust and the UK government health departments, to help establish the MRC-led Health Data Research UK, of which the Wales and Northern Ireland site, directed by Professor Ronan Lyons of Swansea University, is an integral part.

We also continue to invest in the NIHR-run Health Technology Assessment, Health Services and Delivery, and Public Health Research programmes, and the NIHR/MRC Efficacy and Mechanism Evaluation programmes. In 2017–18, 31 applications were submitted to these schemes led by Welsh applicants or institutions, 8 of which were successful. 102 applications were submitted with co-applicants from Wales (including those which were led from Wales), of which 27 were successful⁴³.





Case study

Involving the public to ensure research value/impact

Diabetes and related metabolic conditions are a leading cause of ill-health and premature mortality across the UK, putting huge financial pressures on health services. The Diabetes Research Unit Cymru (DRU Cymru) aims to address the health burden caused by diabetes in Wales by bringing together researchers, clinicians and patients to improve the quality of diabetes research and care.

The USTEKID Study

Approximately 3000 people a year are diagnosed with new onset type 1 diabetes across the UK, with over half of them being young people and children under the age of eighteen. The USTEKID study is looking at the effectiveness of a monoclonal antibody (ustekinumab) as a means of preserving insulin producing cells in young people with recent onset type 1 diabetes. The study could show that interrupting the destruction of the insulin producing cells at the time of diagnosis may preserve and maintain some insulin secreting capacity, potentially improving the long-term control of diabetes.

The Diabetes Research Unit Cymru (DRU Cymru) successfully secured five years of funding from the National Institute of Health Research Efficacy and Mechanism Evaluation (NIHR EME) programme for this study, the first successful bid from Wales. The funding contribution from Health and Care Research Wales opens the EME programme to researchers based in Wales.

Patient and Public Involvement

Making sure that research is relevant to and benefits the people it is meant to be helping is essential and the DRU Cymru public engagement team ensured that the views of people with diabetes were taken into account in designing the USTEKID study. A focus group assessed the study procedures and discussed with the Chief Investigator how acceptable and practical these would be to potential participants.

The feedback from the young people and their parents informed the final study design and a study specific information film has now been produced.

The engagement team also arranged for participant information sheets to be reviewed by young people of a similar age to those the study is aimed at, prior to review by the ethics committee. A parent contributor from the DRU Cymru Public Reference Panel then attended the ethics committee meeting with the study team to provide a public perspective on the study.

"For this trial, we need volunteers aged 12–18 years. The Patient and Public Involvement team at Health and Care Research Wales advised us that a 3–4 minute 'clickable' online film would help teenagers and their families see and understand what the study involves better than a traditional written information sheet – so we made the first video patient information sheet. DRU Cymru advised us on a film-maker and the Public Involvement team and families with type 1 diabetes guided us on style and content with a great result."

Professor Colin Dayan, Chief Investigator.

Laboratory

Input from the DRU Cymru laboratory team was integral to the design of the study protocol and site sampling manual. The laboratory team advised on the sample collection, storage and analysis processes as well as the logistics of transport of sample collection kits and subsequent temperature controlled transport of study samples from the multiple study sites across the UK. In future, the DRU Cymru laboratory will carry out analysis of study samples; this will include both rapid testing and reporting to determine a participant's eligibility for the trial and longer-term 'batched' analysis of samples from enrolled participants over the planned four and a half year duration of the study.

Type 1 Diabetes UK Immunotherapy Consortium (T1D UK)

The USTEKID Study will be delivered through the Type 1 Diabetes UK Immunotherapy Consortium (T1D UK) with support from the Swansea Trials Unit. The T1D UK consortium has been funded by Diabetes UK and the Juvenile Diabetes Research Foundation (JDRF) since 2015 to promote, develop and support immunotherapy research in type 1 diabetes. The consortium has established a network of 15 research sites strategically distributed across the UK, including Cardiff and Swansea.



Research improving the health of future generations

Wales is leading the way in combating childhood obesity now and for future generations as research finds better ways of enabling children and young people to lead healthy lives, contributing to a healthier, more active Wales.

This year, the number of children dangerously obese by the time they leave primary school will be ten times higher than in the 1990s, and that's a trend that looks set to continue.

Now Wales is pioneering steps to tackle this well into the next 70 years through research harnessing health and activity data from primary and secondary schools, and trials aiming to boost activity by giving young people greater choice.

Changing the research landscape

Wales' National Centre for Population Health and Wellbeing Research (NCPHWR) is at the forefront of research to inform obesity prevention initiatives. Funded by Health and Care Research Wales, the Centre has forged its own path in finding the evidence to develop new approaches.

Professor Sinead Brophy, deputy director of NCPHWR, explains: *"Taking interventions that work for adults and directly applying them to young people as a quick fix has been done in the past and there is little evidence that this works."*

"We're taking a very different approach by developing solutions that young people want, and are sustainable by understanding the issues from the perspective of young people."

Creating a national health network

With a strong focus on literacy and numeracy, it can be difficult for schools to support the health and wellbeing needs of children.

To combat this Wales has established the Health and Attainment of Pupils in Primary Education Network (HAPPEN), which has collected health and activity data on over 4000 pupils from schools across Swansea. This data is helping those schools to spot and tackle health inequalities amongst their students.

According to one deputy head teacher, HAPPEN is already helping to *"increase the opportunities that children receive"*, and the HAPPEN team believe that it could form the basis for a national schools health programme into the next 70 years. *"As a network we are looking to expand across Wales and to provide Wales with a national Primary School Health Network,"* explains Emily Marchant, HAPPEN coordinator

This year, the number of children dangerously obese by the time they leave primary school will be **ten times** higher than in the 1990s



British children and young people remain among the least active in the world.

Asking the right questions

Beyond primary school, obesity in childhood has serious impacts on young people's growth and development, and later life health. With evidence showing that obese children are staying obese for longer, it's more important than ever that researchers are asking the right questions to create positive change for future generations.

In response, the NCPHWR have developed the largest network of secondary school age health and activity research in the world, with the aim of creating healthy futures for young people.

By collecting data twice a year from more than 100,000 students in secondary schools across Wales, the School Health Research Network (SHRN) allows schools to better understand the challenges facing them, and allows researchers to identify the questions that need answering.

Professor Simon Murphy, principal investigator at SHRN, said: *"We are able to identify the health issues that need addressing, highlight chalk face approaches that are making a difference and work together to develop evidence based approaches that will improve the prospects of future generations."*

Over the next 70 years, SHRN data could be used to conduct more research into the most important and pressing topics in children's health leading to developments in policy and practice.

Letting teens make their own choices

Although policy makers are looking at the evidence and attempting to implement physical activity schemes for young people, British children and young people remain among the least active in the world.

Leading researchers in Wales think they have found the missing link – the teens themselves, their needs and their wants.

That's why on top of collecting data to inform schools, the National Centre is trialling new approaches that treat teenagers as individuals and allowing them to make their own decisions about exercise.

The Active Children through Individual Vouchers Evaluation (ACTIVE) project gave activity vouchers to year nine pupils, aged 13 to 14, to spend on any physical activity they like, empowering young people to make their own decisions, changing attitudes and decreasing inactivity.

Teenagers who took part also gave recommendations about what would make them want to take part in physical activity, including lower costs, having local facilities and dedicated activities for teens.

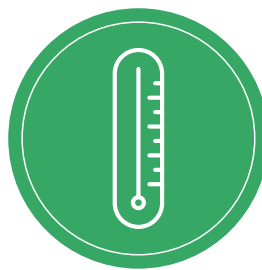
Michaela James, ACTIVE trial manager, said: *"We are definitely looking into future funding for ACTIVE. Our hopes are that we can answer some questions we have from our findings to develop an even better intervention to help teenagers become more active."*

By considering the teens own recommendations when implementing schemes and policies of the future we may be able to encourage teenagers to lead more active lives.

Impacting Wales as a whole

Young people are our future and so their health is of vital importance to us all, research conducted by the Centre is protecting children's health now and for the future generations of Wales.

Ronan Lyons, director of NCPHWR, said: *"The work being carried out can have a positive impact, not just on young people and their future achievements, health and wellbeing, but potentially on the future productivity and health of Wales as a whole."*



Case study

Fuel Poverty Data Linkage Project

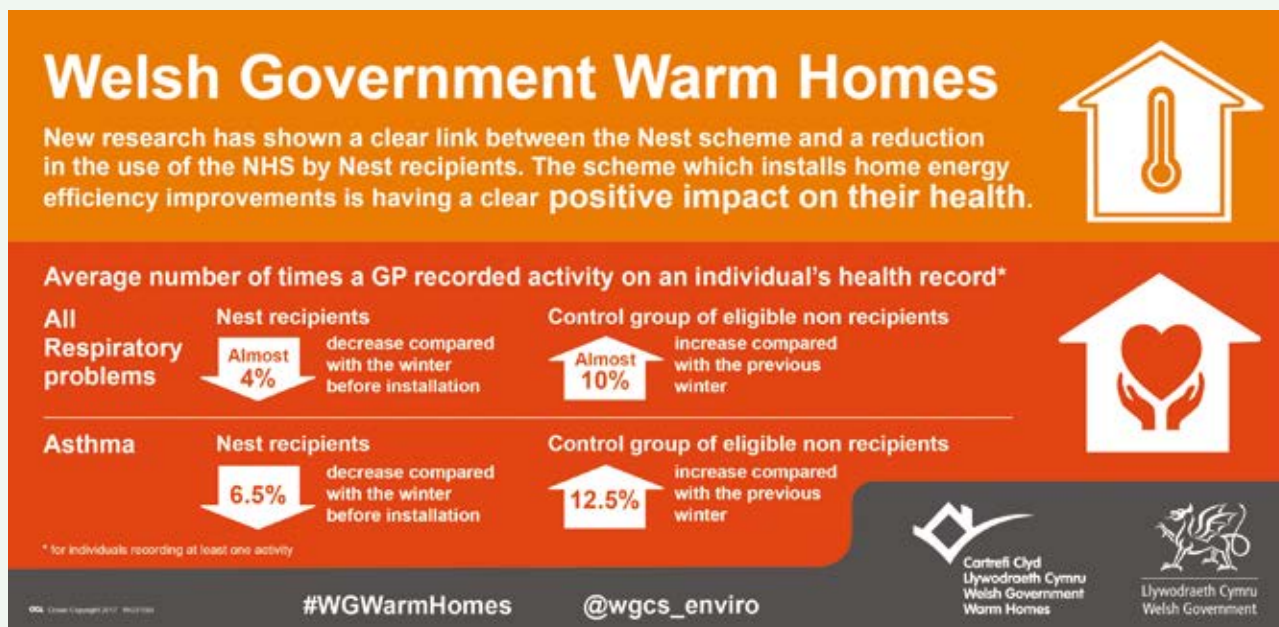
As part of its strategy to reduce fuel poverty in Wales, the Welsh Government implemented a demand-led fuel poverty scheme called Nest to improve the energy efficiency of homes. The project, a collaboration between Welsh Government Energy Policy, Welsh Government Knowledge and Analytical Services and the SAIL Databank, used SAIL Databank data linking and research capability to explore the impact of the Warm Homes Nest scheme on health outcomes. Using linked health, warm homes and other datasets the study examined the impact of the current scheme on hospital admissions and general health for recipients of home energy efficiency measures.

The research has had an impact on Welsh Government policy, directly informing debate and consultation on the successor scheme, providing justification for the continuation of funding to the successor scheme and informing the decision to extend eligibility to low income people with

respiratory and circulatory conditions. Due to the success of the initial project it has been awarded further funding for 2018–21.

"Findings from the study have directly supported decisions on policy including the targeting and eligibility of our energy efficiency and fuel poverty programme. In particular, they have informed our decision to extend eligibility for free home energy efficiency improvement measures to low income homes where people suffer with respiratory or circulatory health conditions. We are currently piloting this through our Warm Homes Nest scheme. The positive findings have also assisted us in engaging with health partners by demonstrating clear benefits to the health of recipients and reduced use of our National Health Service. It is an excellent example of the potential for data linking to improve the delivery of public services".

Figure 8





Research Informing policy

Secure Anonymised Information Linkage – SAIL – Databank

Since 2007, the Health Informatics Group at Swansea University has been custodian of the Secure Anonymised Information Linkage (SAIL) Databank. This is a safe haven of billions of anonymised person-based records about the population of Wales with in-built tools for conducting data linkage and analysis. The technology underpinning the SAIL Databank was developed over many years, and is internationally recognised as world leading innovation in data de-identification, security and linkage.

The ability to link multiple sources of data together that relate to e.g. a particular individual, a geographical location or an event, brings a new dimension to answering research questions. Data linkage allows

researchers to use existing collections of extensive data that have been routinely collected and stored securely to identify patterns across entire populations to give a much broader picture. Research using data from SAIL has the potential to impact significantly and positively on a range of areas affecting health and wellbeing.

Research using data from SAIL has the potential to impact significantly and positively on a range of areas affecting health and wellbeing.

Case study

Family attitudes, actions, decision and experiences following implementation of deemed consent and the Human Transplantation Act (Wales)

Led by Professor Jane Noyes of Bangor University, this important and highly topical study was awarded funding under the prudent healthcare theme of the Health Research Grants call 2015.

The project explores the impact of a new system of presumed consent to organ donation. To achieve this, the project team took a co-productive approach, partnering with Welsh Government, NHS Blood and Transplant (NHSBT), and patient and public representatives. They collected a range of data using a mixed methods approach, including:

Interviews with family members and family questionnaires

Interviews and focus groups with specialist nurses in organ donation, managers, trainers and regional managers

Routinely collected NSHBT data and Welsh Government data

Anonymously shared data logs and field notes

Key findings so far include:

Overall, consent to organ donation improved from 48% to 61% of cases, but the number of transplants stayed the same.

The media campaign would have been improved if it had better explained how family members were no longer the decision-makers for organ donation. Families are now encouraged to support the donation decision that their relative made during life.

People can make their organ donation decision known in a variety of ways (including taking about it and registering on the organ donor register), but this has resulted in a more complex system for specialist nurses to document and manage.

Family members went on to override the organ donation decision of their relative 31 times out of 205 cases.

Most family members the project team spoke to did not accept that 'doing nothing' (deemed consent) was a positive choice that supported organ donation.

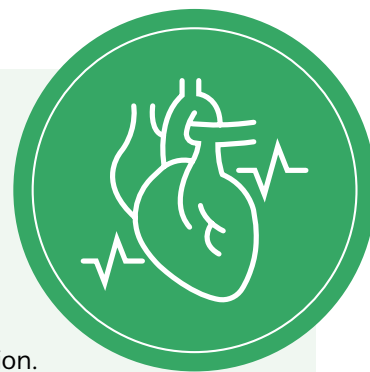
Family members were required to produce written evidence or have had a witnessed conversation to override their relative's organ donation decision, but the project team found this unrealistic to implement in practice.

Key impacts of the study so far include:

A new media campaign has been launched, focusing on the changed role of the family in decision-making.

Additional retraining has been designed for specialist nurses and professionals to help unpick the deceased person's decision from the personal views and decisions of family members

The findings are being considered by policy-makers in Scotland, England and the Netherlands. Australia is also considering a change to organ transplantation after evaluating the impact in the UK.





Wales' role in the genomic revolution

New genetic and genomic technologies are allowing us to develop a much more detailed understanding of the link between our genes and health. Genomic medicine is an emerging technology driven approach for the prevention, diagnosis and treatment of disease in which testing for changes or variants in the genome (genetic makeup) of a patient, tumour or infectious agent informs clinical decision-making.

In recent years there has been international recognition that these technologies have the potential to revolutionise medicine and public health. New genetic and genomic technologies are allowing us to develop a much more detailed understanding of the link between our genes and health. In recent years there has been international recognition that these technologies have the potential to revolutionise medicine and public health. The pace of change in this area is rapid.

Genomic testing, getting a picture of all the genetic material that shapes each of us, has the potential to allow researchers to develop personalised, targeted treatments rather than a 'one size fits all' approach.

This 'personal touch' could unlock a whole new world of options for people living

with rare diseases: faster diagnosis, new treatments, where currently there are none, and an end to the uncertainty of how their disease might develop.

Part of everyday medicine

Precision medicine is all about getting the treatment that's right for you, and crucially, at the right time.

The Welsh Government's ambitious plan, the 'Genomics for Precision Medicine Strategy', aims to ensure everyone in Wales has access to cutting-edge genetic and genomic testing.

"The strategy really does represent something of a step-change in the level of commitment in Wales to making these technologies work in the context of the NHS, and in biomedical research," said Professor Julian Sampson, director of the Health and Care Research Wales funded Wales Gene Park.

The plan aims to make Wales an international leader in precision medicine, with experts working closely together to make genomics and genetics part of everyday medicine.

The Genomics Partnership Wales is the focus for this, bringing together organisations including the All Wales Medical Genetics Service, Public Health Wales and the Wales Gene Park.



Your genome

is the instructions
for making and
maintaining
you

Your genome
contains

20,000
genes

Understanding genomes

Your genome is the instructions for making and maintaining you. Everything in the living world has a genome, from us to plants, bacteria, viruses and animals, written in the same four letter chemical code contained in the molecule DNA.

Your genome contains around 20,000 genes, the instructions for making the proteins our bodies are built of – from the keratin in hair and fingernails to the antibody proteins that fight infection.

But genes only make up about 1–5% of your 3.2 billion letter genome, with the rest thought to be ‘junk’ DNA, with little purpose other than as packaging around the genes. But it’s now known to have critical roles in how the code is read, like helping to ensure genes are switched on and off at the right time as we grow.

Changing lives

For those with rare diseases unique to them and maybe a few others in the world, there is no off-the-shelf diagnostic test or treatment, meaning years, or even a lifetime of uncertainty and distress.

Scanning their entire genomes for small changes in the code, perhaps just one letter’s difference, could pinpoint the cause of their condition but this remains cutting edge, costly science.

Now, Wales is part of the ground-breaking 100,000 Genomes Project, aiming to show how this could be done. A world first, it aims to sequence (decode) 100,000 genomes from 70,000 people with rare diseases and their families, as well as those with cancer.

“Patients in Wales with rare conditions in whom routine testing failed to make a diagnosis now have a chance to access the most comprehensive genetic test available; sequencing of their entire genome,”

said Professor Julian Sampson, who leads the project in Wales. *“This will increase the chances of achieving a specific diagnosis to inform their healthcare.”*

“Wales’ participation in this UK-wide project is helping to establish genomic medicine in the NHS. This will have far-reaching benefits for the understanding, diagnosis and treatment of many conditions.”

Already making a difference

Genomic medicine is already advancing our understanding of diseases like cancer and Alzheimer’s disease, with discoveries that could transform patient care.

Researchers from Cardiff University’s School of Medicine, led by Professor Duncan Baird, have developed a new test that could give blood cancer patients more certainty, and help design individual treatments for them.

The test measures the length of telomeres; protective stretches of DNA that cap the end of the DNA packages, or chromosomes, which our genome is sorted into. Those chromosomes divide to make new copies each time a new cell is made, with telomeres acting like plastic shoelace tips, preventing the chromosome ends from fraying or sticking as they divide.

Genomic medicine
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Shorter DNA structures can leave chromosome ends exposed, accelerating cancer progression and drug resistance.

“Our research provides strong evidence that shortening of telomeres plays a vital role in the progression of these blood cancers and that a significant number of patients should be receiving different levels of treatment,”

said Professor Baird, Wales Cancer Research Centre Lead for Cancer Genetics and Genomic Instability.

Professor Baird and his team’s telomere length test gives a highly accurate indicator of disease progression for those with myeloma, causing life threatening bone marrow failure, and pre-leukaemia myelodysplastic syndromes – bone marrow disorders that often lead to acute myeloid leukaemia, a blood cancer that is difficult to treat and cure.

Similar hope for better prediction and management of Alzheimer’s has come from the discovery of two new genes linked to people’s risk of the condition, by researchers at the Medical Research Centre for Neuropsychiatric Genetics and Genomics. The Centre is the first of its kind in Wales and the largest psychiatric genetics group in the UK. It is hoped this discovery could lead to new screening tests and personalised treatments for patients living with the disease.

The next generation of genomics researchers

Health and Care Research Wales’ commitment to driving Wales’ precision medicine forward through research is clear, with many of its funded centres and units carrying out or supporting precision medicine research.

Growing the next generation of genomics researchers is critical to this and the recently awarded Sêr Cymru Precision Medicine Fellowships, part-funded by the European Regional Development Fund through the Welsh Government – in collaboration with

NHS and higher education institutions in Wales – will support early-stage researchers tackling key health issues, including resistance to antibiotics.





A global health issue that threatens to make common illnesses and routine procedures lethal once more as antibiotics become increasingly ineffective, the fight against antibiotic resistance demands new understanding and tools – with those new approaches coming from unexpected places.

Initial studies have shown that a low molecular weight alginate extracted from seaweed can increase the effectiveness of antibiotics when treating highly resistant bacteria.

Research fellow, Dr Manon Pritchard, is now leading a study to find out exactly how the 'seaweed' affects the behaviour of bacteria and its ability to make antibiotics more effective. That information could then be used to develop new treatments for patients

with conditions like serious lung infections in cystic fibrosis, where current antibiotics may become ineffective.

Other research fellowship projects will use the findings from genomic testing to develop potential treatments for liver disease, colorectal cancer and acute myeloid leukaemia.

Chief Scientific Adviser for Wales, Peter Halligan said: *"I am really pleased and impressed to see how working collaboratively with our partners is driving Welsh investment in building research capacity and capability in keeping with the aims of the Welsh Government strategy Science for Wales."*

Recommendations

Coordinate Activity

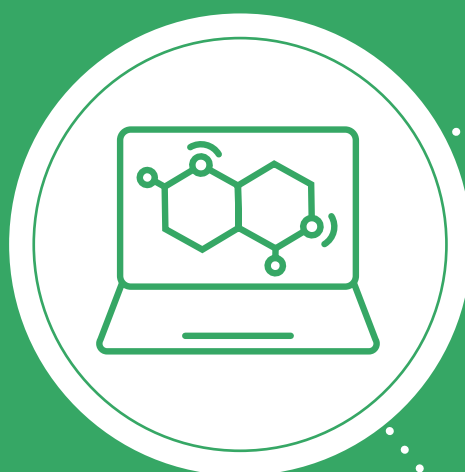
There should be continued and coordinated investment in research and innovation. Cross public sector work engaging key stakeholders in the design, delivery and implementation of research and innovation should be improved for the benefit of the people of Wales.

Continue to fund impactful research

Research which has the potential to have a positive impact on the health, wealth and well-being of the people of Wales should be funded as a priority. The Welsh Government must continue to work with partners to realise the value of research.

Increase public involvement opportunities

The research community in Wales, supported by the Welsh Government, should continue to work with and for the public to increase opportunities for patients, service users, carers and the public across Wales to be involved in research.







4. Working together to protect the public from health threats

Legislation is a
powerful
tool in tackling public
health issues



Preventing and controlling infections that are likely to be treated with antimicrobials is one way of reducing the need for antibiotics.

Public Health Wales (Act) 2017

Legislation is a powerful tool in tackling public health issues. The Public Health (Wales) Act 2017⁴⁴ has so far provided protection for young people by prohibiting the intimate body piercing of children under 18 and established a process to encourage improved planning of provision and access to toilets for use by the public⁴⁵.

The health threats we currently face

A range of health protection threats and harms currently exist such as healthcare acquired infections, anti-vaccination campaigns, antibiotic overuse and resistance, imported high consequence infections, and changing environment threats. Health security has become a greater public health priority, whether from chemicals, radiation, nuclear or other environmental effects including climate change. In Wales, we have responded to a significant number of public health threats in the last year. Statistics on the wide range of communicable disease threats are provided by Public Health Wales and are included at **Annex A**.

The response to threats requires early detection, good planning and the application of resources in collaboration with others. We need to continue to invest in our health protection services and infrastructure to ensure we remain resilient to the threats we face.

Threats from Antimicrobial Resistance

Antimicrobial resistance is an increasing problem in Wales and has already led to a small number of difficult to treat infections

in all health board areas, leading to failed therapy and potential complications.

During the 5-year period, 2013/14 to 2017/18, health and social care in Wales focused their efforts on the prevention and control of healthcare associated infections and reduction in inappropriate use of antibiotics. Over this time period there was an 11.9%⁴⁶ reduction in total antibacterial usage across GP practices in Wales. Current data shows that this downward trend is continuing through 2018/19 in support of the 5%⁴⁷ reduction in total antimicrobial volume goal set by Welsh Government for this financial year. So progress has been made but we need continue to work with GP practices in Wales to ensure appropriate antibacterial use.

Preventing and controlling infections that are likely to be treated with antimicrobials is one way of reducing the need for antibiotics. The UK's five-year national action plan⁴⁸ (2019–2024) sets new target for the UK. One priority area for action is to reduce the incidence of drug resistant infections by 10% by 2025 and halve the number of healthcare associated gram-negative blood stream infections by 2021. The national action plan also sets reduction targets for antimicrobial use. Antimicrobial usage is to reduce by 15% by 2025, including a 25% reduction in antibiotic use in the community and a 10% reduction in use of antibiotics in hospitals.

These reduction expectations will be challenging for health and social care services and there is an urgent need for resources to be available in community settings to support infection prevention and antimicrobial stewardship.



In 2017–18 just
820,000
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against flu

Representing
25%
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of Wales

Threats from vaccine preventable diseases

In 2017–18 we saw the highest numbers of flu cases diagnosed in general practices and hospitals since the 2009 pandemic⁴⁹. In addition 88⁵⁰ outbreaks of acute respiratory illness were reported across hospitals and care homes.

Flu vaccination offers the best protection from flu and each year we have seen an increase in the number of individuals who get vaccinated. In 2017–18 just over 820,000⁵¹ people were vaccinated, representing 25% of the population of Wales. Uptake in two and three year olds increased to 50.2%⁵² and in four to eight year olds increased to 68.3%⁵³.

The vaccination of children reduces their risk of catching flu but also reduces the amount of flu circulating in the community. In 2017–18 the Welsh Government expanded the flu vaccine offer for primary school children to children in Year 4 (programme now covers reception class to Year 4)⁵⁴. For 2018–19 the Welsh Government will be expanding the flu vaccine offer to all children in primary school (by adding Year 5 and 6 to the programme).

Elderly residents living together in close proximity where flu can spread easily are particularly vulnerable and so for 2018–19, as well as vaccinating the residents, staff working in adult residential care homes and nursing homes were offered flu vaccination through their community pharmacy.

Outbreaks of measles can cause significant harm to individuals and take significant NHS resources to contain. The UK has again retained its status of effectively eliminating measles⁵⁵ thanks to the hard work undertaken by surveillance and health protection teams to limit the impact of imported cases of this serious disease. The Measles, Mumps and Rubella (MMR)

vaccine is a safe and effective vaccine⁵⁶.

The 2017–18 annual report on vaccine uptake in children in Wales shows that uptake of the first dose of MMR vaccine in two year old children remains below 95%⁵⁷ and the uptake of two doses of MMR by children aged five years was below 90%⁵⁸. It is important that professionals have the right information to give to parents to counteract the impact of anti-vaccination campaigns.

There are currently a large number of measles outbreaks in many countries in Europe with most cases and fatalities occurring in unvaccinated adults and children⁵⁹. In 2017–18 we saw measles cases in Wales imported from these affected countries. We can expect these sporadic cases to continue while so many of our children are unprotected.

Nearly every year there is a tragic death of a student from meningococcal disease⁶⁰. New university entrants are at particular risk of getting the disease as they are likely to be mixing closely with many new people, some of whom will unknowingly carry meningococcal bacteria. As such, all new university entrants should be vaccinated before the start of the new academic term (or as soon as possible after). Based on data for the age groups turning 19, 20 and 21 during 2017–18 it is estimated that uptake in university entrants is around 40%⁶¹, so six out of ten students starting this academic year are unprotected. Practice nurses should remember to check that students have received the MenACWY vaccine.

The infections discussed above are vaccine preventable and we need to take every opportunity to continue to promote uptake, particularly through the use of effective social marketing.



Continue to promote
vaccine uptake, particularly
through the use of
social media

Exposures to environmental hazards across Wales continue to pose health risks for individuals and communities alike.

Threats from treatable communicable diseases

New anti-viral medications have revolutionised the treatment of hepatitis C so the disease is now, to all intents and purposes, curable. Treatments are well tolerated and of relatively short duration. This fundamental change in treatment provides an opportunity to significantly reduce hepatitis C in all communities across Wales.

In 2017–18 a framework was communicated to NHS Wales setting out what services they need to provide to deliver on the government's commitment to eradicate hepatitis B and C as a significant public health threat⁶². We have made a good start but there are challenges to overcome if we are to succeed. Testing and treating in the community must become a reality if we are to achieve the commitment. The longer the estimated infected 12,000⁶³ or so individuals in Wales remain untreated the more the infection will spread in the community, creating a greater problem for the future.

Sexually transmitted infections continue to rise⁶⁴. A review of sexual health services in Wales, undertaken by Public Health Wales, was published in early 2018⁶⁵. Its nine key recommendations have been accepted by the Welsh Government and are being taken forward under the oversight of the Sexual Health Programme Board. These recommendations when implemented will see improvement in case management, access to services and improved patient experience.

Threats from our environment

Exposures to environmental hazards across Wales continue to pose health risks for individuals and communities alike. These may arise because of natural

phenomena such as flooding, or extreme heat and cold weather conditions, or accidental (even deliberate) releases of pollutants, chemicals and radiation.

In 2017–18, Public Health Wales' Environmental Public Health Team⁶⁶ responded to around 500 separate requests for advice and support from partner agencies to help assess and manage risks. This included 274 incidents, 90 environmental health enquiries and 129 land-use planning / environmental permit consultations. Service demands continue to increase year on year.

Chemical contamination of air, water and land caused most public health concern⁶⁷. In addition, Public Health Wales supported partner agencies and the public in understanding the risk and providing advice on health protection measures for the many grass fires seen during the summer of 2017.

The harms air pollution has on health are well documented⁶⁸. A Welsh Government-led Clean Air Programme has been established to develop and take forward an ambitious Clean Air Plan for Wales. Actions include: reviewing evidence, undertaking research, monitoring and assessing capabilities, improving communications to effect behaviour change and greater integration across sectors (transport, planning, industry, agriculture and public health).

There is a need to develop air quality and health surveillance capabilities, risk assessment methodologies and embed public health in transport, planning and environmental sustainability policy and practice.



Recommendations

Managing the threats from Antimicrobial Resistance (AMR) and other high consequence infectious disease

There is an urgent need for resources to be made available in community settings to support infection prevention and antimicrobial stewardship and we need to continue to invest in our health protection services and infrastructure to ensure we remain resilient.

Eliminating hepatitis as significant public health threat

Health boards should invest in community services so that populations at risk of hepatitis C are tested and referred to treatment where necessary.

Increase vaccine uptake

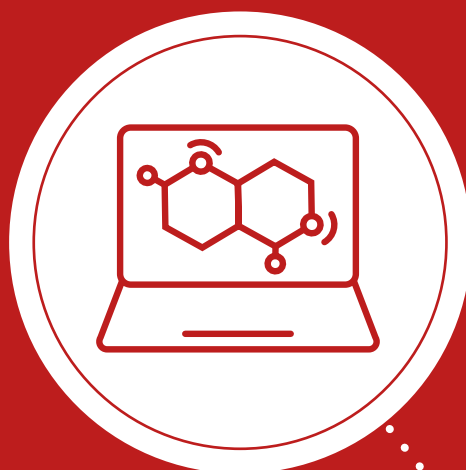
Welsh Government, Public Health Wales and NHS Wales need to take every opportunity to continue to promote uptake, particularly through the use of effective social marketing.

Reducing sexually transmitted infections

The nine recommendations identified through the independent review of sexual health services in Wales and accepted by Welsh Government should be implemented as soon as practicable in order to improve services and patient experience and ultimately reduce infections.

Improving air quality

Air quality and health surveillance capabilities and risk assessment methodologies require investment and public health must be embedded in transport, planning and environmental sustainability policy and practice.





Annex A.

Communicable Disease.

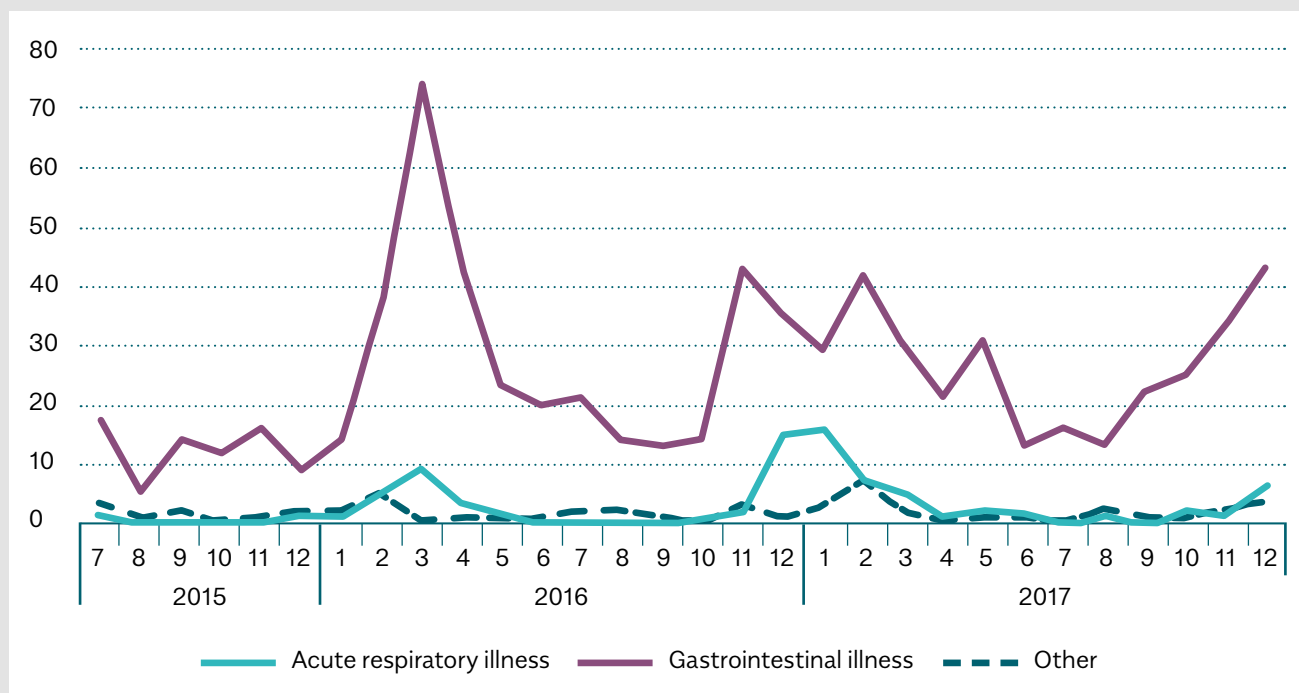
Notifiable diseases and organisms and outbreaks reported to CDSC 2017.

A full list of notifiable diseases can be found on the Public Health Wales website at www.wales.nhs.uk/sites3/page.cfm?orgid=457&pid=48544#a

Table 1: Outbreaks and incidents reported to the CDSC by setting, 2017

Setting	Acute respiratory illness	Gastro-intestinal illness	Other	Total
Residential home	18	138	10	166
Hospital	23	79	2	104
School	0	49	6	55
Other	1	20	3	24
Nursery	0	17	3	20
Restaurant / hotel / pub / takeaway	0	11	0	11
Prison	0	2	0	2
Farm	0	1	0	1
Travel abroad	0	1	0	1
Total	42	318	24	384

Figure 9: Outbreaks reported by month¹ reported, from July 2015 (when reporting started) to December 2017.



¹ Month of report generated using date of report. If date of report was not available, date of onset used. If date of onset was not available then date of report generated using the Monday of the week reported.

Table 2: Number of diseases notified⁶, 2017⁷

Notifiable disease	Frequency
Encephalitis (acute)	3
Enteric fever (typhoid or paratyphoid fever)	6
Food poisoning	3,587
Haemolytic uraemic syndrome (HUS)	5
Infectious bloody diarrhoea	3
Infectious hepatitis (acute) ¹	174
Invasive group A streptococcal disease and scarlet fever ²	1,610
Legionnaires' Disease	51
Malaria	16
Measles	236
Meningitis (acute) ³	163
Meningococcal septicaemia ⁴	35
Mumps	522
Rubella	24
Tetanus	1
Tuberculosis	124
Viral haemorrhagic fever (VHF) ⁵	1
Whooping cough	277

¹ Includes Acute Infectious and Acute Viral Hepatitis

² Includes Scarlet Fever and Invasive group A streptococcal disease (IGAS)

³ Includes Acute Meningitis, Meningitis, Meningococcal diseases, Meningococcal meningitis and TB meningitis

⁴ Includes meningococcal septicaemia and 'meningitis and septicaemia'

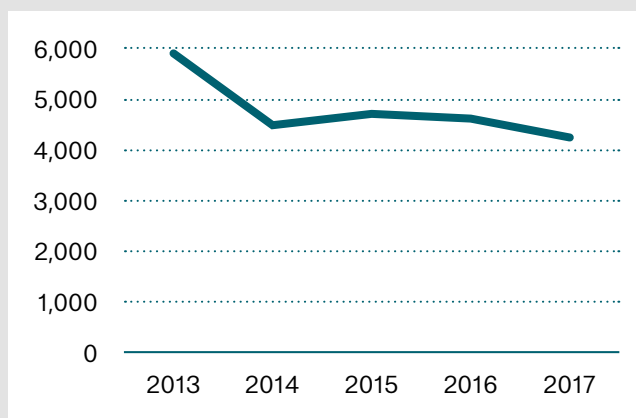
⁵ Includes Dengue fever, Ebola haemorrhagic fever and Viral haemorrhagic fever

⁶ Notifications of diseases diagnosed clinically may not correlate to a laboratory confirmed case

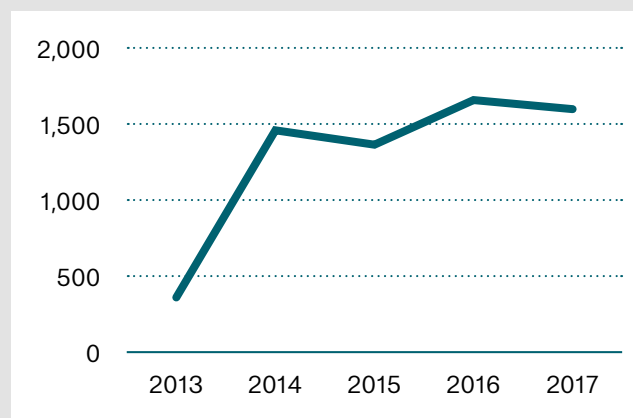
⁷ There were no reported notifications of Anthrax, Botulism, Brucellosis, Diphtheria, Leprosy, Plague, Rabies, SARS, or Yellow Fever in 2017

Figure 10: Annual disease notifications by year and disease category

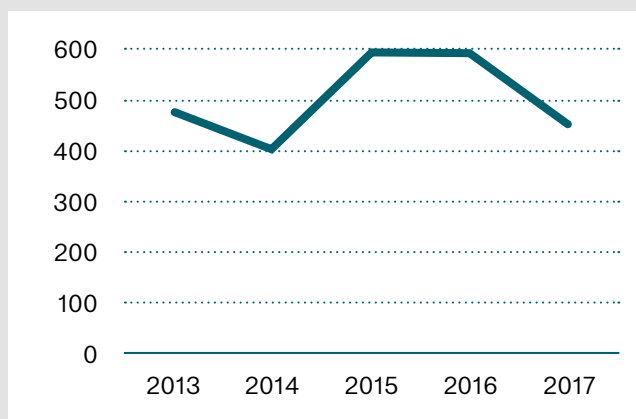
Gastroenteritis¹



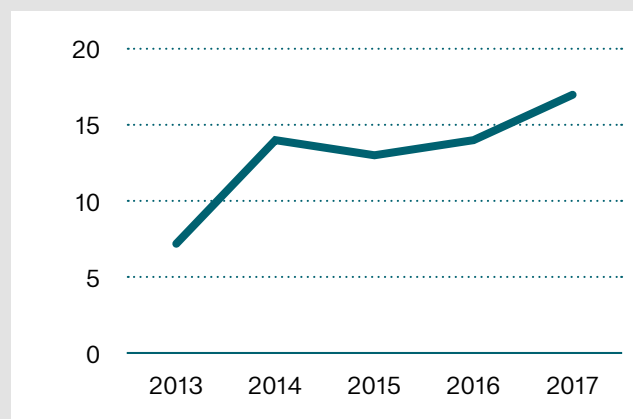
Scarlet fever and iGAS



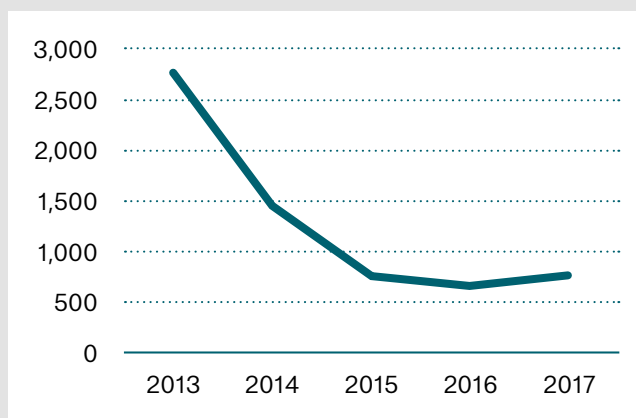
Respiratory²



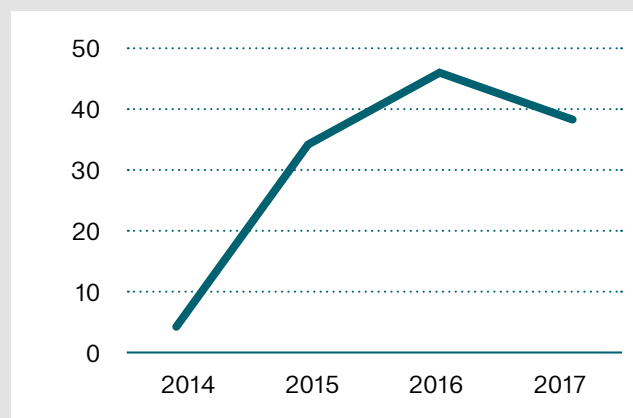
Vector/Zoonotic⁴



Mumps and Measles



Lyme Disease



¹ Gastroenteritis diseases includes Cholera, Enteric fever, Food poisoning, Haemolytic uraemic syndrome, and Infectious bloody diarrhoea

² Respiratory diseases include Legionnaires Disease, Tuberculosis and Whooping Cough.

³ Methods of reporting of Hepatitis updated in 2014

⁴ Vector/Zoonotic includes Brucellosis, Malaria, Plague, Rabies, Typhus and Yellow Fever

Table 3: Number of notifications of laboratory confirmed organisms⁶, 2017⁷

Notifiable organism	Frequency
Bordetella pertussis	24
Borrelia spp	55
Campylobacter spp	3,616
Clostridium perfringens ¹	17
Cryptosporidium spp	347
Giardia lamblia	123
Hepatitis A	59
Hepatitis B ²	271
Hepatitis C ²	599
Hepatitis E	47
Influenza virus	1215
Legionella spp ³	46
Listeria monocytogenes	8
Measles virus	22
Mumps virus	10
Mycobacterium tuberculosis complex ⁴	71
Neisseria meningitidis	44
Rubella virus	1
Salmonella Typhi or Paratyphi	10
Salmonella spp ⁵	372
Shigella spp	21
Varicella zoster virus	177
Verocytotoxigenic Escherichia coli (including E.coli O157) ³	29

¹ Only if associated with food poisoning

² Results may include repeated tests on the same patient with chronic Hepatitis

³ Results are for tests done in Welsh laboratories and may not have been confirmed by UK national reference laboratories

⁴ Includes Mycobacterium africanum, Mycobacterium bovis and Mycobacterium tuberculosis

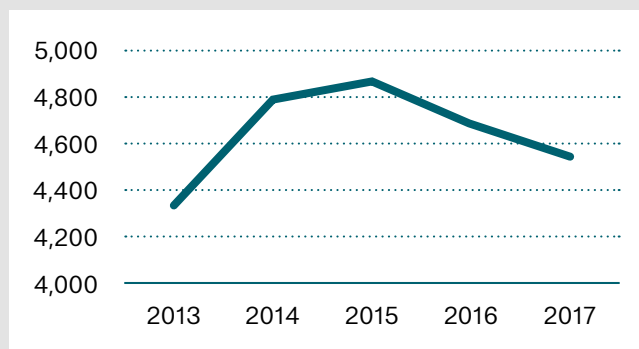
⁵ Not including Salmonella typhi or paratyphi

⁶ Samples tested in non-Welsh laboratories may not be included

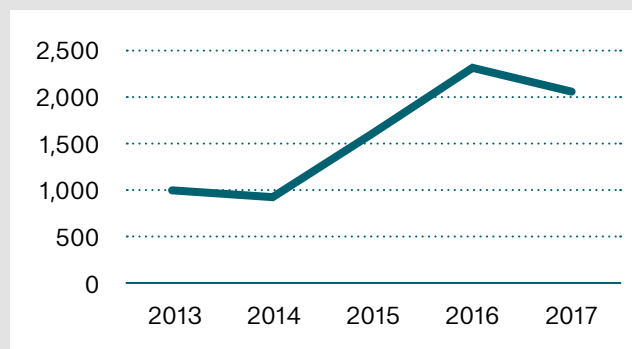
⁷ There were no reported notifications of Chlamydia psittaci, Coxiella burnetii, Leptospira interrogans, Brucella, Chikungunya Virus, Clostridium botulinum, Corynebacterium ulcerans in 2017

Figure 11: Annual disease notifications by year and disease category

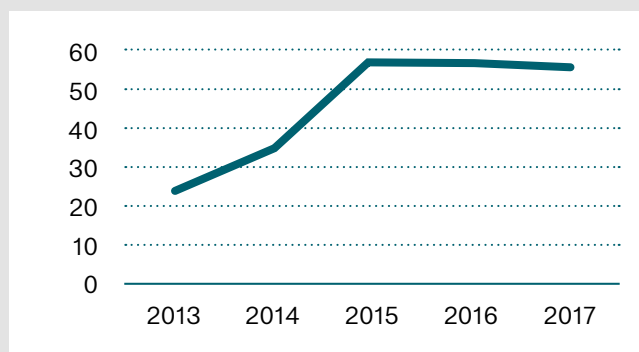
Gastroenteritis¹



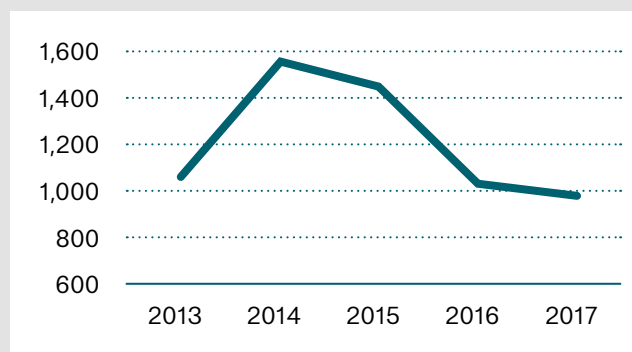
Respiratory²



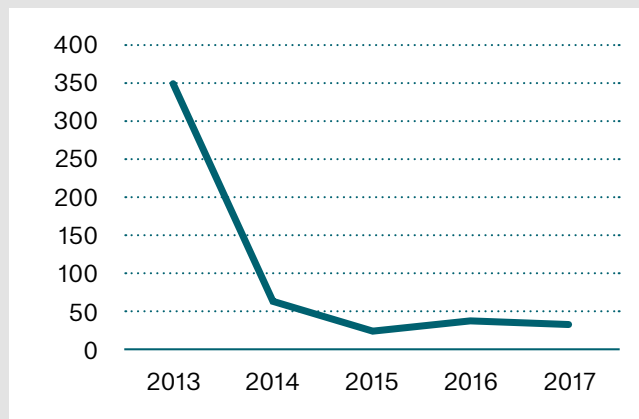
Vector/Zoonotic³



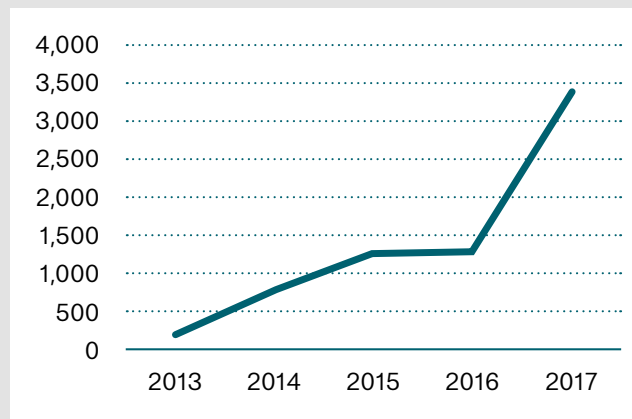
Hepatitis



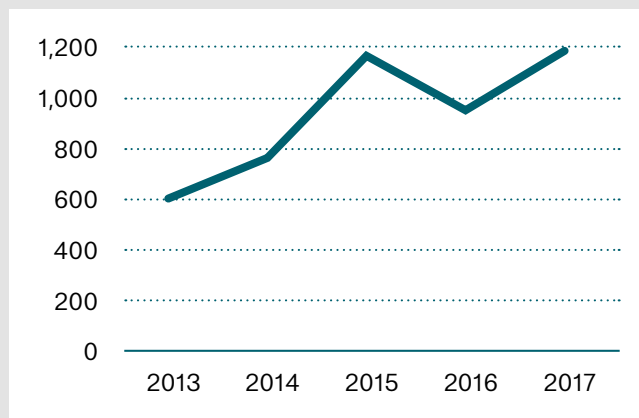
Mumps and Measles



Influenza⁴



Neisseria gonorrhoeae



¹ Gastroenteritis includes *Entamoeba histolytica*, *Vibrio cholera*, *Bacillus cereus* (food poisoning only), *Campylobacter* spp, *Clostridium perfringens* (food poisoning only), *Cryptosporidium* spp, *Giardia lamblia*, *Listeria monocytogenes*, *Salmonella Typhi* or *Paratyphi*, *Salmonella* spp, *Shigella* spp and Verotoxigenic, *Escherichia Coli*.

² Respiratory includes *Haemophilus influenza*, *Streptococcus pneumoniae*, *Bordetella pertussis*, *Influenza virus*, *Legionella* spp, *Mycobacterium tuberculosis* complex, *Rubella virus*, *Varicella zoster virus*.

³ Vector/Zoonotic includes *Bacillus anthracis*, *Brucella* spp, *Chikungunya virus*, *Dengue virus*, *Francisella tularensis*, *Plasmodium (falciparum, vivax, ovale malariae, knowlesi)*, *Rabies virus* (classical rabies) and rabies-related lyssaviruses, *Rift Valley fever virus*, *West Nile Virus*, *Yellow fever virus*, *Yersinia pestis*, *Borrelia* spp, *Chlamydia psittaci*, *Coxiella burnetii*, *Hanta virus*, *Leptospira interrogans* and *Rickettsia* spp

⁴ Number of notifications is per financial year.

Annex B.

Gambling-related harm.

Updated since 2016–17

Recommendations on action to tackle public health harms from problem gambling – November 2018.

The Welsh Government has been working across portfolios to identify actions that can be taken to reduce the prevalence of problem gambling and the impact it has on health and wider society, in line with the recommendations in last year's Annual Report. A Welsh Government officials' group has been established to develop a strategic approach on action to reducing gambling-related harm across Wales, and improve the co-ordination and promotion of existing prevention and treatment services.

This Group has been collaborating with third sector providers and other partners to build on the good work already going on in Wales and to drive the shift towards a population approach to tackle the harm from gambling. For example, discussions are ongoing with Public Health Wales (PHW) as to how problem gambling can be integrated as a topic in the Making Every Contact Count initiative in Wales. PHW and Bangor University have written a joint report on Gambling and Public Health, which draws on

a report by Bangor University on the spatial distribution analyses of gambling related issues across Wales⁶⁹. Welsh Government will consider this evidence and ask local authorities to do the same to help inform local and national actions to prevent gambling related harms across Wales. The next review of Healthy Working Wales will consider how advice to employers on action to reduce gambling-related harm could be incorporated. Advice to highlight the risks and links between online gaming and gambling-type behaviours has been added to a social media and gaming workshop resource for parents and carers provided via the Welsh Government's Hwb⁷⁰.

The Group has also been engaging with GambleAware – who have a responsibility to fund research and treatment, and to increase awareness of gambling-related harm across Great Britain – to increase their presence and activity in Wales. As a result, GambleAware are making their resources available in the Welsh language



so that they may be incorporated into lesson plans and displayed in GP surgeries across Wales. The Group will work with GambleAware as they take action to increase the number of sites in Wales where treatment services are offered by GamCare and raise awareness of these services. The Group has also liaised with GambleAware on the creation of a Welsh Advisory Panel, consisting of representatives from the public health community, to further inform their activity in Wales.

The Welsh Government co-hosted a roundtable discussion with the Gambling Commission in January. This brought together key stakeholders to raise the profile of gambling as a public health issue and help to inform future action by both the Welsh Government and the Gambling Commission in Wales.

The prevalence of gambling and problem gambling in Wales has to date been monitored through survey work commissioned by the Gambling Commission. The Welsh Government arranged to include questions on gambling in the Health Behaviour in School-aged Children/School Health Research Network survey during 2017/18; the results of which will be published in spring 2019. Questions on frequency, participation and attitudes to gambling will also be included in the National Survey for the first time in 2020–21. This will enable the prevalence of gambling behaviours to be analysed against other public health issues such as alcohol consumption and mental health.

In September, the Welsh Government brokered a seminar with DECIPHer at Cardiff University that brought together researchers and academics with an interest in gambling-related harm⁷¹. Information gathered from the seminar will be used to inform future research by the DECIPHer team. Swansea University has been funded by the Forces in Mind Trust to undertake the first ever UK survey to understand and explore the levels of gambling participation and attitudes to gambling in ex-Service personnel. Welsh Government officials are in contact with the research team and will be promoting awareness of the research study to maximise take up in Wales.

The Welsh Government has consulted on proposed changes to the Town and Country Planning (Use Classes) Order 1987⁷² which included a proposal to require each new betting office to be considered through a planning application. This change would enable future policy intervention through the planning system should research





confirm a causal relationship between, for example, an 'over-concentration' of betting offices increasing levels of gambling-related harm. Welsh Government officials have also approached Directors of Public Protection Wales (DPPW) to consider further the role of local authorities in action to prevent gambling-related harm. DPPW agree that there is an opportunity for local authorities to contribute towards efforts here such as embedding the Health Impact Assessment process into the planning and licensing regime; consultation with DPPW on how to achieve this is ongoing.

The Welsh Government has continued to urge the UK Government to do more to tackle the public health concerns and to maximise the various options available to address the issue of problematic gambling. For example, in April the Cabinet Secretary for Health and Social Service issued a joint letter with the Leader of the House to the Advertising Standards Authority (ASA) to raise their concerns about the proliferation of gambling advertising on television and online, particularly in relation to how they influence the vulnerable and, especially children and young people. The Cabinet Secretary also wrote to the Minister for Sport and Civil Society to express his disappointment at the initial delay to the implementation of changes

to the maximum stake for fixed odds betting terminals (FOBTs) given the wide-ranging impacts that will be prolonged by such a decision. The UK Government has since announced that they will implement the maximum stake of £2 by April 2019. A decision has been made not to use the powers in the Gambling Act 2005 prior to the implementation of the policy changes by the UK Government due to the very limited impact this would have before the UK Government's changes take effect in April 2019.

The Welsh Government is committed to progressing further action against the recommendations in Gambling with our Health in the coming year.



The Welsh Government has continued to urge the UK Government to do more to tackle the public health concerns and maximise the various options available to address the issue of problematic gambling.

Annex C.

Statistical annex.

Notifiable diseases and organisms and outbreaks reported to CDSC 2017.

A full list of notifiable diseases can be found on the Public Health Wales website at www.wales.nhs.uk/sites3/page.cfm?orgid=457&pid=48544#a

Figure 12: Deaths, all causes, 2001–2017

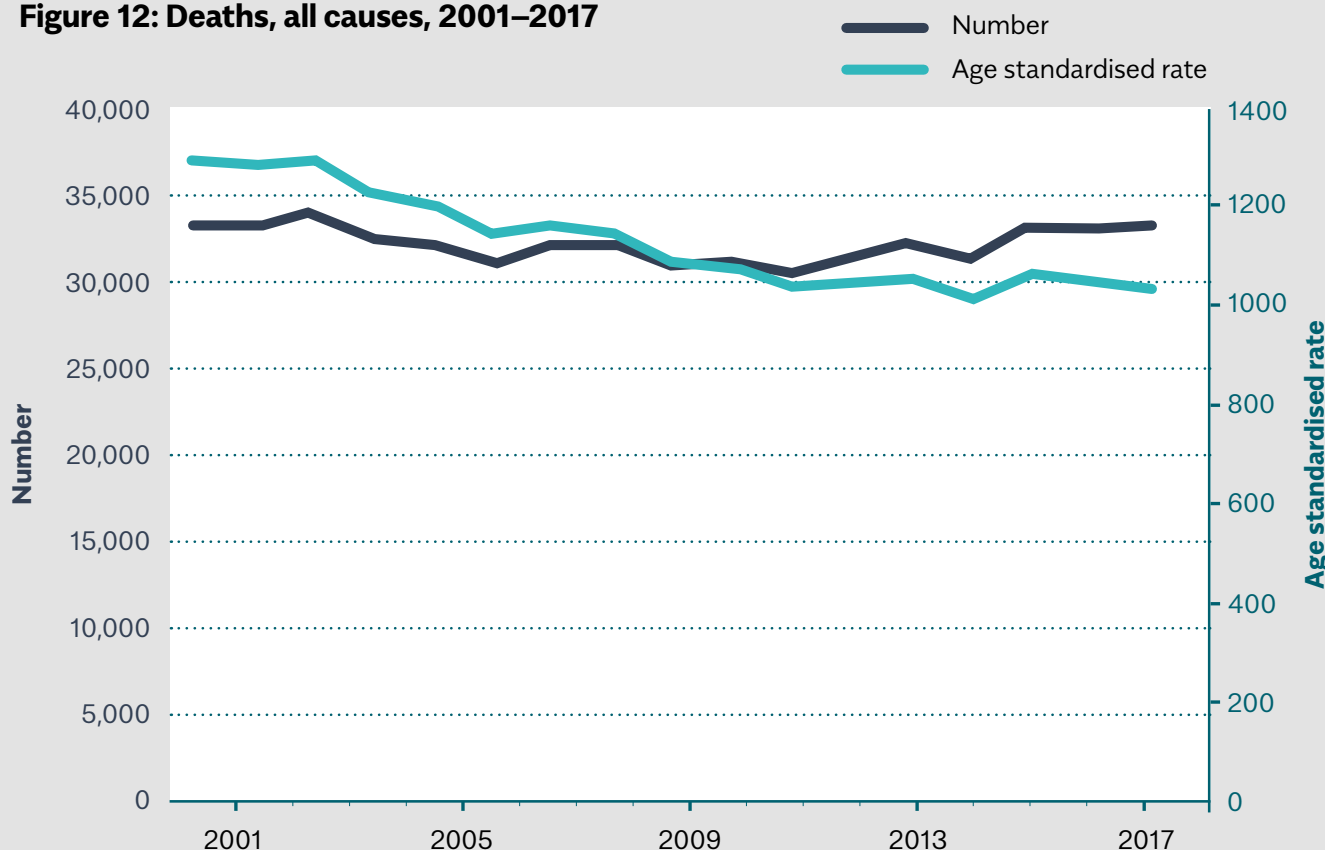


Figure 13: Death rates, selected causes, 2001–2017

Source: NHS Digital Services

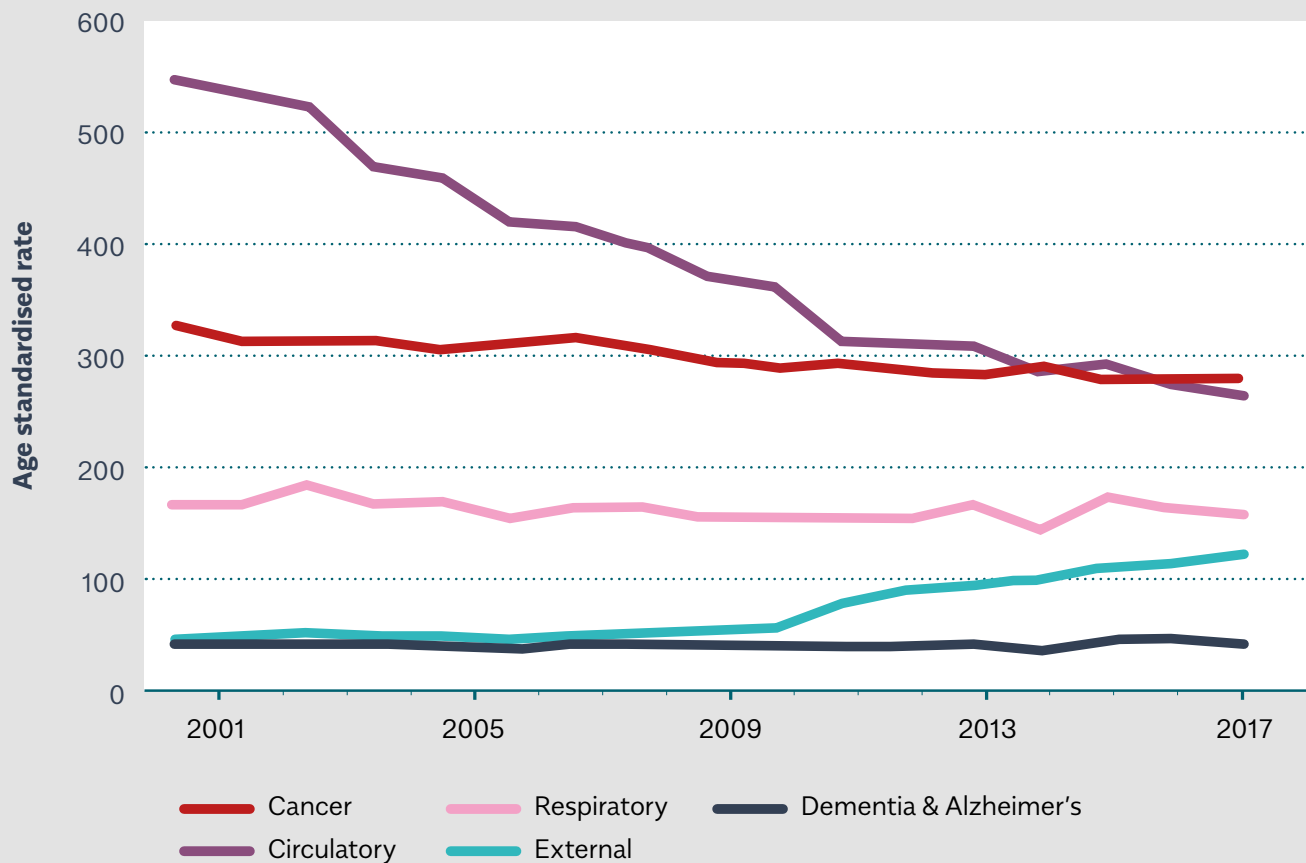


Figure 14: Life expectancy at birth, 2001–2003 to 2015–2017

Source: Office for National Statistics

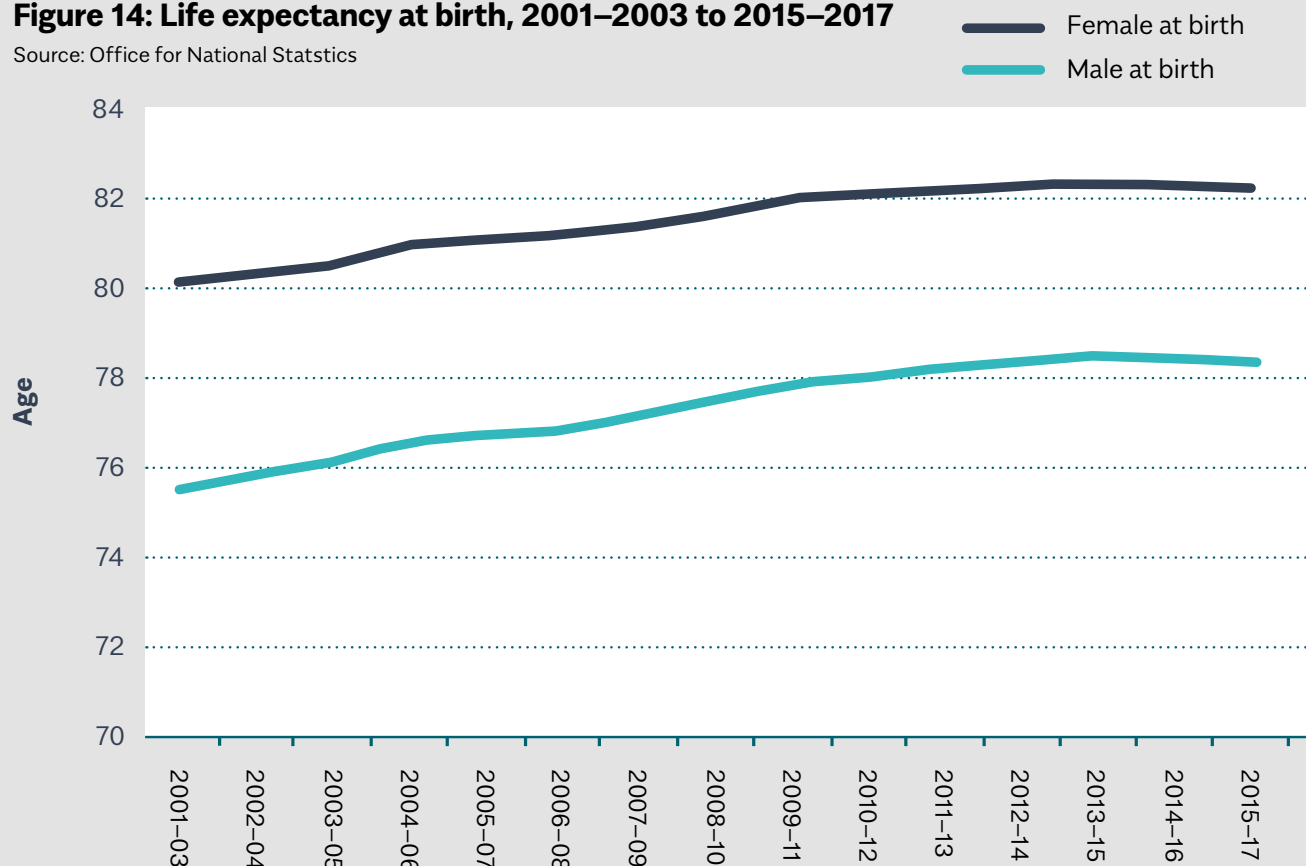


Figure 15: Life expectancy age 65, 2001–2003 to 2015–2017

Source: Office for National Statistics

Female at 65
Male at 65

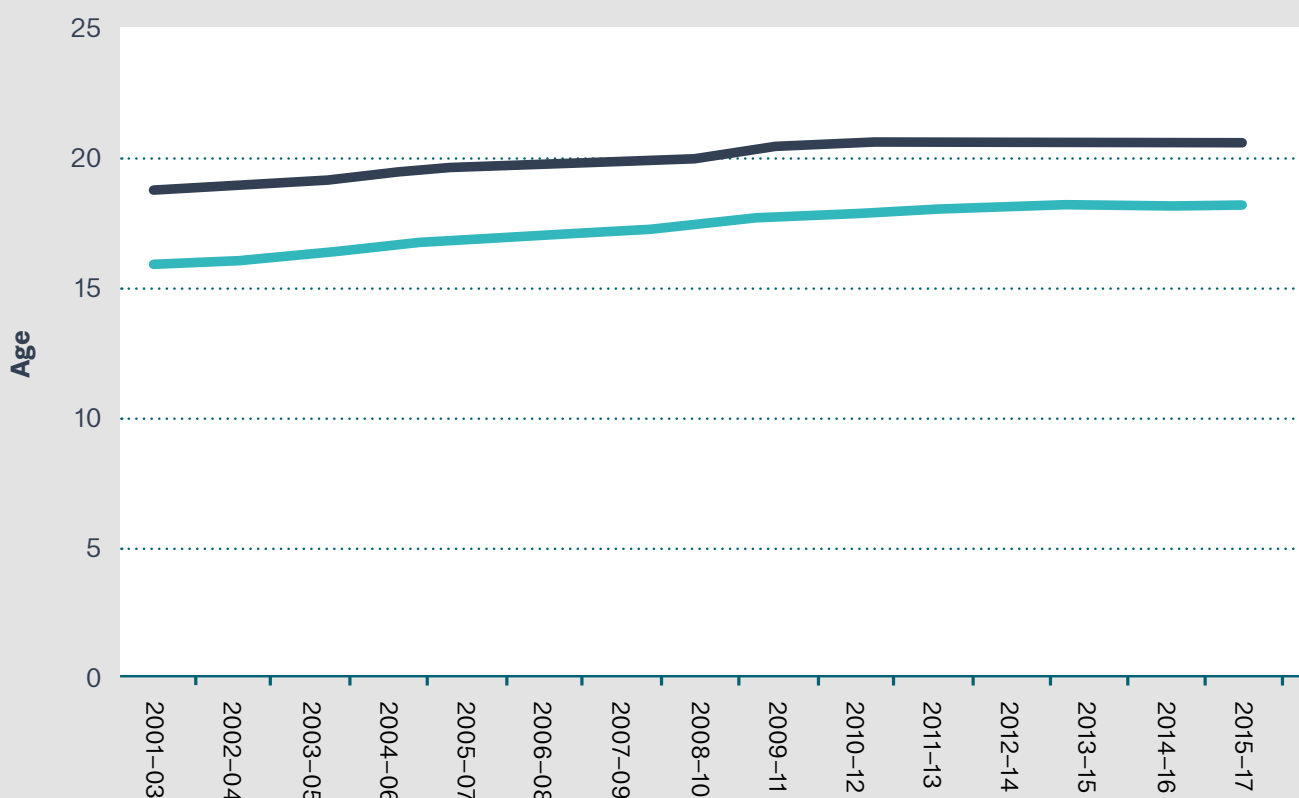


Figure 16: Adults following healthy lifestyle behaviours, by deprivation quintile, 2017–18

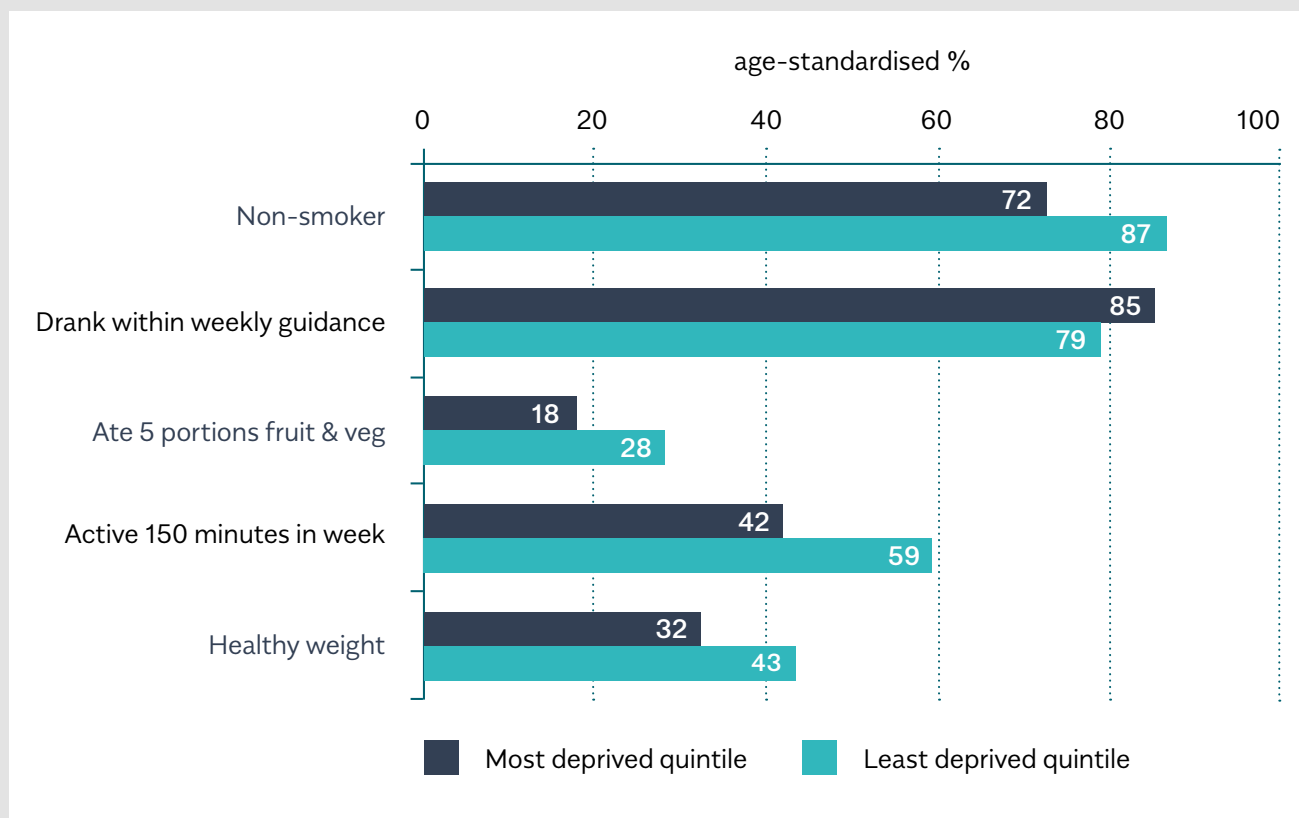
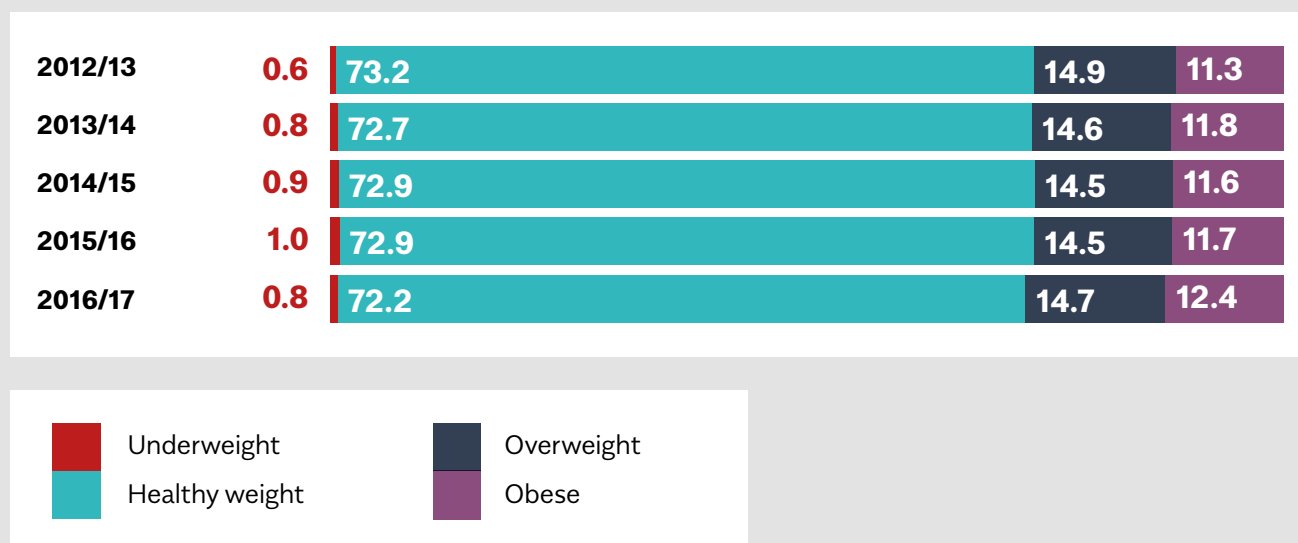
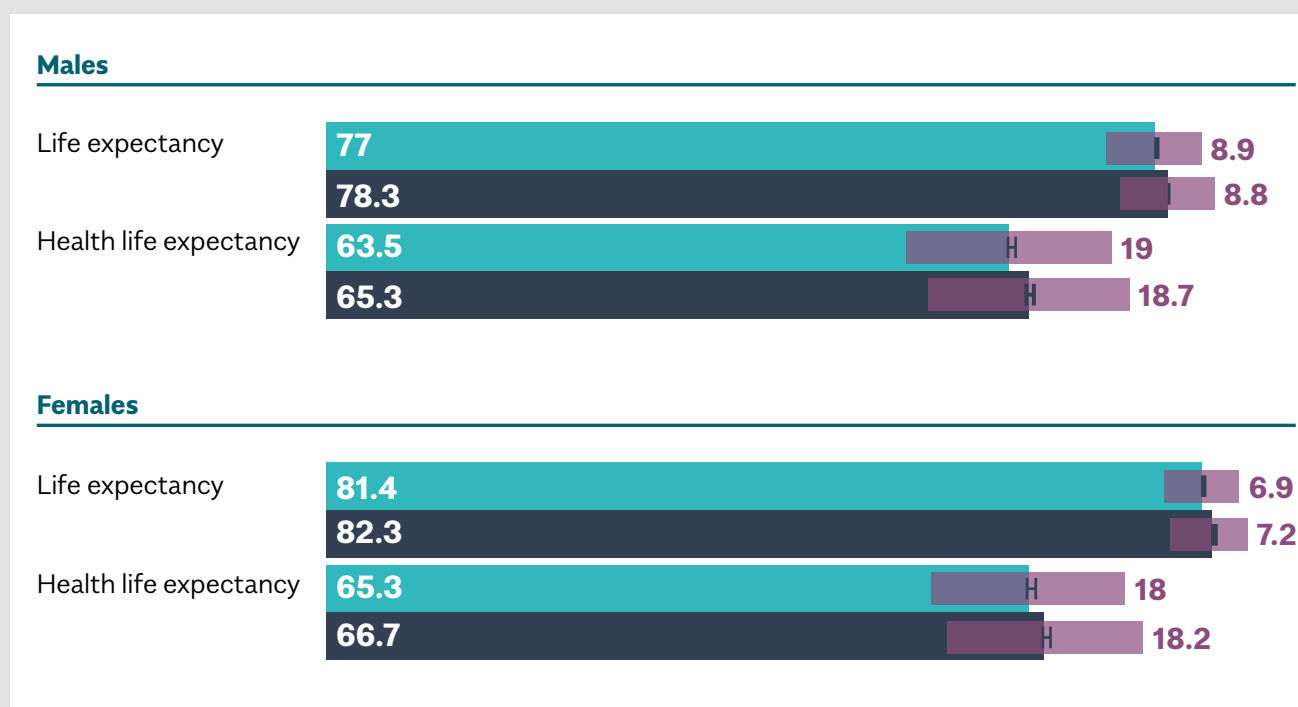


Figure 17: Percentage of children aged 4 to 5 years who are underweight, healthy weight, overweight or obese 2012–13 to 2016–17



Produced by Public Health Wales Observatory using CMP data (NWIS)

Figure 18: Comparison of life expectancy and healthy life expectancy at birth, with Slope Index Inequality (SII), 2005–2009 and 2010–2014



Produced by Public Health Wales Observatory, using PHM & MYE (ONS), WHS & WIMD 2014 (WG)

Figure 19: Smoking rates among adolescents (years 7–11), 1986–2014

Pupils in years 7, 9, 11. *Data for 2018 is provisional; data collection moved online for 2018 which may effect comparability

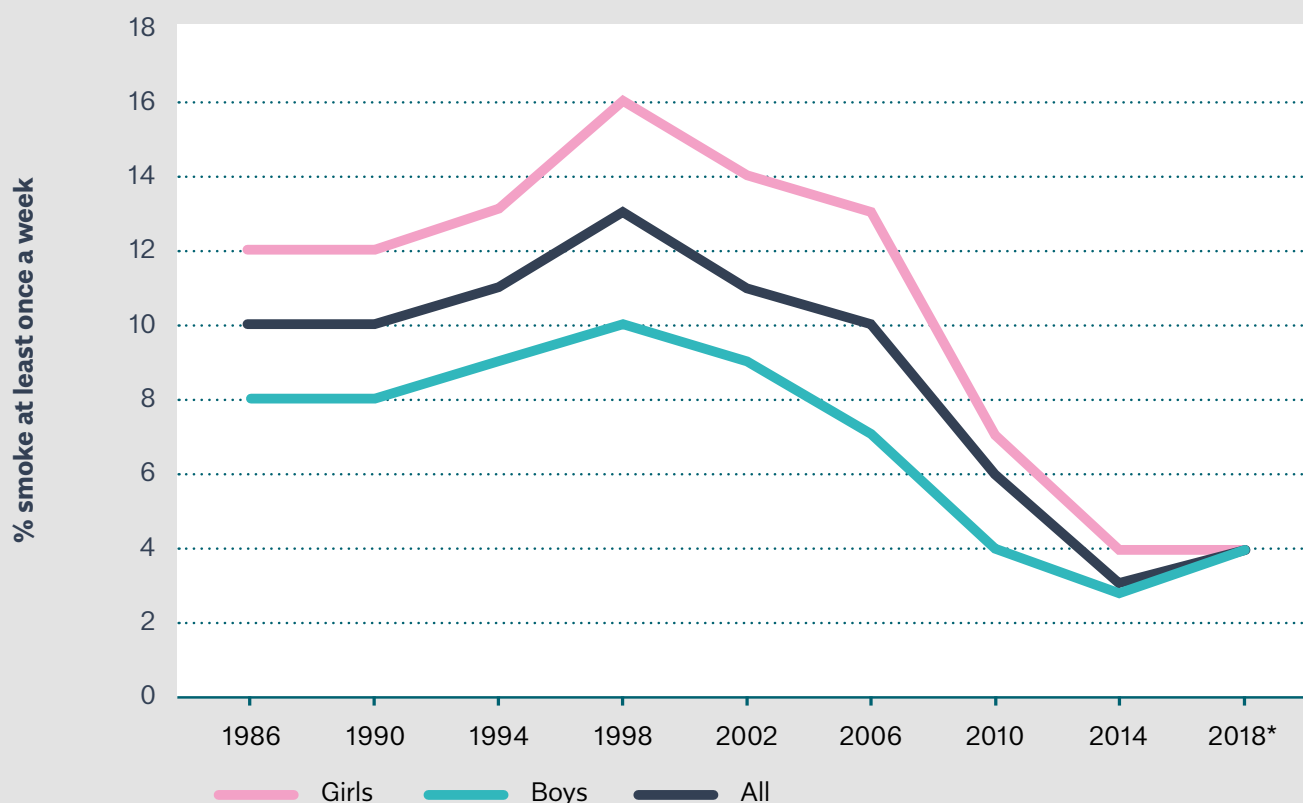
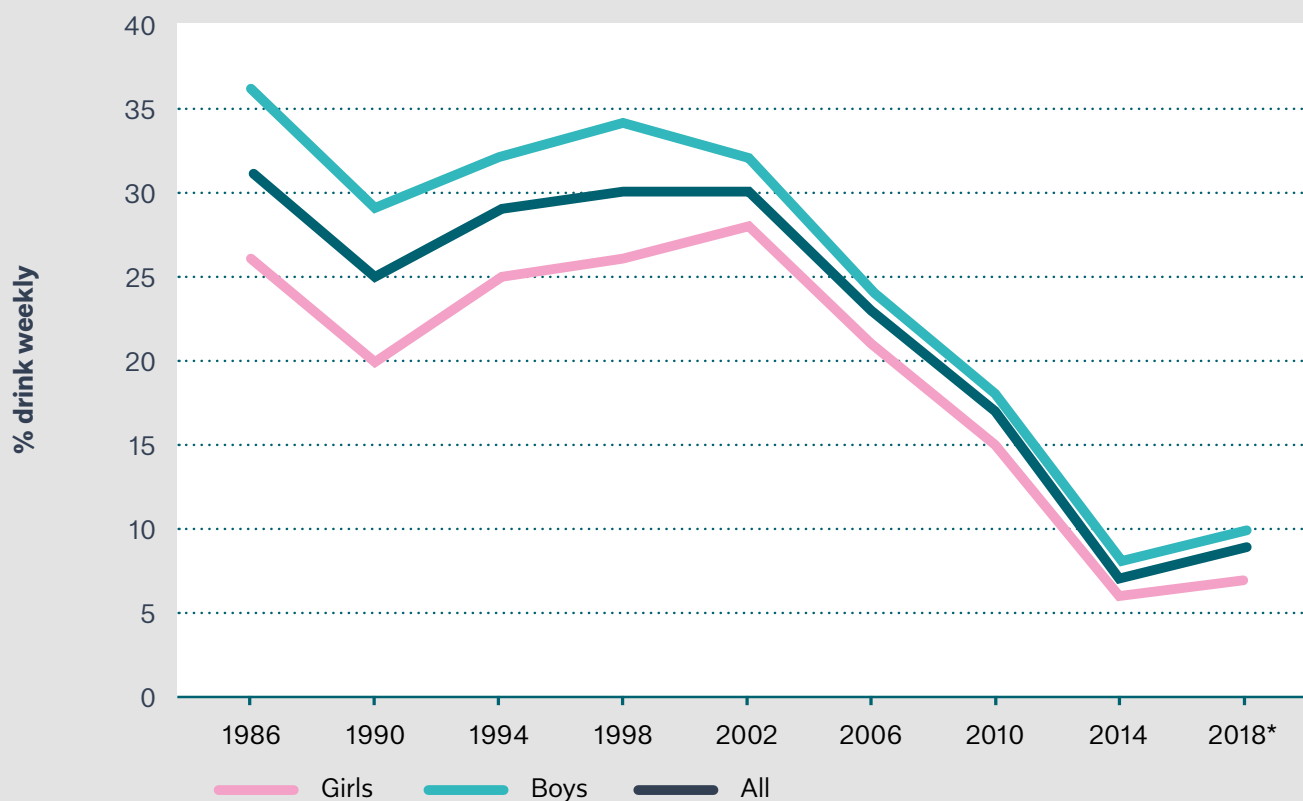


Figure 20: Drinking rates among adolescents (years 7–11), 1986–2014

Pupils in years 7, 9, 11. *Data for 2018 is provisional; data collection moved online for 2018 which may effect comparability



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