Comisiwn Bevan Commission

Covid-19 Intelligence Series: Data collection, collation and communication

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The Limits of Science

Covid-19 currently dominates our public and private lives. As such it is unsurprising that it is the subject of 24/7 coverage by every type of media. There is a constant barrage of data, information, facts, opinion and conjecture-with the distinction between them often not apparent…or declared. Trying to make sense of all this for those used to data has been challenging, let alone those who are less familiar. It begs the questions – what data are we using (is it consistent, can we compare?) how are we using it (does it inform plans and actions?) and how might we best communicate it most effectively and meaningfully?

There have been appeals that 'we should all follow the science' and claims that policy 'follows the science' has become a cloak that politicians (of all parties and in every country) like to wear. Over time it has become apparent that 'the science' is often ambiguous in its findings and liable to different interpretations. There are two main reasons for this. One is that Covid-19 is such a new disease. Accordingly much is still unknown, or subject to hypothesis, where only time and painstaking research can show if they are correct. Where there is uncertainty, the usefulness of 'the science' as a sure guide to action rapidly diminishes.

The second point is of a more fundamental and profound nature. Where there are trade-offs to be made between desirable objectives, in many cases science cannot provide a neat (or perhaps any) answer. For example, the desire to minimise loss of life to Covid-19 and the desire to ensure people with other life threatening diseases are treated, or that economic activity is maintained, or that people do not suffer the derogatory effects of social isolation and lack of physical activity, all require a judgement to be made, and all carry a loss as well as a gain.

When people make statements in relation to Covid-19 that 'you can't put a price on life' they appear to have forgotten that historically the National Institute for Health and Care Excellence (NICE) has attempted to do just that through Quality-Adjusted Life Years (QALY) calculations. Science helped guide what factors should be considered, what the evidence of health improvement for various treatments actually is and the methodology for cost/life years gained, but cannot answer if it should then be applied…or even where the cost threshold should be. Science has little to contribute when it comes to accounting for the personal trauma and loss that the death of a loved one brings. Nevertheless, decisions- however unpalatable- do have to be made.

With these cautionary admonishments in mind, this paper looks at what data are available and what information they convey, in relation to the emotionally charged issue of deaths related to Covid-19. This is a subject where statistics have tended to be 'weaponised' to support the arguments of various camps intent on proving the supremacy of their position and the perfidy of their opponents. Too often, much heat

but little light results. So through the course of this paper we are looking to answer three questions:

1. What does the data tell us?
2. Why so often are only partial understanding or misunderstandings occurring?
3. What can be done to improve matters (in Wales)

Deaths: what should be the measure?

The Office of National Statistics (ONS) provides weekly updates on deaths from all causes (including Covid-19) but only for England and Wales. This information comes from death certificates, and there is a time lag between when an actual death occurs and when it is registered. ONS data is the 'gold standard' in terms of death reporting because it is picking up deaths from all sources (hospitals, care homes, hospices, community) whereas other sources of information such as Public Health Wales and the NHS do not have every possible place of death in their reporting.

In the first few weeks of Covid-19 impacting on the UK this generated some confusion as to how to measure and account for the actual number of deaths attributed to the virus. We can all recall numbers being announced in daily briefings and it subsequently becoming apparent that these were for deaths in hospital only, and not in other places such as care homes. This then led to accusations of under-reporting and also of unfair inter-country comparisons. Subsequently, the reporting of deaths in care homes has improved in such briefings but the truth remains that the most complete picture remains ONS data (and its equivalents in Scotland and Northern Ireland). However those reports are 11 days behind the current position. So, for example this piece is being written on 30th June 2020 and uses the latest ONS data (published on the 30th June) but this only includes deaths up to w/e 19th June (week 25).

It is clear that Covid-19 has had a significant effect on overall mortality in the UK moving 2020 from being (up to March) below the 5yr average for mortality for the first quarter (courtesy of a mild winter and no major influenza season) to a 20 year high in terms of excess deaths. For the UK (as of writing) the peak was reached in week 16 (w/e 17th April) with 9,495 deaths (where Covid-19 was mentioned on the death certificate) and has been falling each week since. Total Covid-19 deaths for the UK in the week ending 19th June (week 25) were 849. For England and Wales only, all deaths (not just those due to Covid-19) in the same week totalled 9,339 compared to 9,404 for the previous 5 year average for that week, after 13 consecutive weeks when they were higher.

Up to week 25, ONS recorded 49,610 Covid-19 related deaths for England and Wales. Excess deaths for 2020 (compared to the five year average) are now at 54,365 which it should be noted is 4,755 more than the total number of Covid-19 deaths. In short, there is excess mortality, not only from Covid-19, but also from

other causes of death. It should also be noted that up to March 13th (week 11) the year 2020 was producing a below average death rate (11,661 deaths per week versus 12,106) compared to the average for the previous 5 years. Weeks 12 to 24 have then averaged 14,540 deaths a week, compared to only 9,976 for the previous five years.

The position in Wales

In summary, the numbers for Wales are:

2020 Total deaths (to week 25)	= 19,160
Total deaths (to week 25) previous 5 years average	= 17,111
Excess deaths	= 2,049 (11.9%)
Total Covid-19 related deaths	= 2,233

So for Wales we (currently) have a different picture from England, with excess deaths totalling less than the Covid-19 mortality (i.e. less people are dying of other things once you exclude Covid-19). Right now these differences between countries can be noted, but not explained. More accurately, various explanations are offered, but at this stage we do know which (if any) are correct.

One can also readily find alternative figures for the excess deaths quoted. One could choose to compare deaths to a particular year, versus a five year average and in doing so the excess deaths figure will be higher or lower depending on the year chosen. One could only include deaths where Covid-19 was shown on the death certificate as the only cause (which would reduce the number). As time goes on, the remainder of 2020 may end having a less than an average number of deaths. It could of course be more, in part because of the effect on mortality of the focus on Covid-19 by the NHS at the expense of treatments for other life threatening diseases such as cancers. In either case, the excess deaths number would change. The danger is that people latch onto a number to support a pre-determined position (known in psychology as affirmation bias) and ignore other evidence that doesn't support their argument.

Deaths in Care Homes

A high number of deaths in care homes due to Covid-19 is not peculiar to the UK as similar levels of deaths are being reported in many countries. This is unsurprising, as care home residents (with and without nursing provision) typically comprise some of the most vulnerable groups if exposed to the virus. Most are elderly and many already in poor health. Of all Covid-19 deaths reported in the UK, those aged 75+ comprise 74.3% of all deaths[1] although they represent only 8.3% of the population[2].

In terms of Covid-19 deaths reported in care homes the ONS figures show that (as of 19th June 2020) 29.68% of all Covid-19 deaths (14,658) have been in a care home. In Wales there have been 670 Covid -19 related deaths (27.9% of all Covid-19 deaths) in care homes as of week 25. Wales has around 26,000 care home beds (with and without nursing)[3] and assuming C.85% occupancy this has meant an overall death rate (year to date) of around 300 per 10,000 care home residents. This compares with under 7 per 10,000 population for England and Wales as a whole.

These are indicative rates only, as a more sophisticated analysis would need to take account of turnover in homes and the fact that death rates vary by week. The risk of catching Covid-19 is less as of week 24 than it was in week 16, because the virus is less prevalent. However the risk to an individual should they have the misfortune to become infected then depends on individual factors such as their sex, state of health, ethnicity etc. Notwithstanding this, it is clear that care home residents are considerably more at risk than the population as a whole.

That risk may be greater than the ONS data describes. The two main reasons why that is likely to be the case are:

One, the process by which deaths are assigned as due to Covid-19 is not always black and white, nor is it infallible. In the absence of a confirmatory test (and testing has been one of the most problematic areas of the UK response to the Covid-19 crisis) whether someone has died of Covid-19 cannot be known for sure and there has sometimes been a reluctance to attribute a death to Covid-19 in the absence of such a test.

Two, the focus on care homes-by both governments and the media came some considerable time after the focus on the NHS. The care sector has, with justification, felt the poor relation in this crisis, whether the issue be access to Personal Protective Equipment (PPE) for staff and residents, testing or reporting. Care Home reporting of deaths is now undertaken on a daily basis (as per hospitals) but historical reporting is likely to underestimate the true impact of Covid-19.

Understanding the wider context

There is a clear need to place the statistics in relation to Covid-19 deaths into context. The news has a tendency to highlight additional Covid-19 deaths that day without placing that number within the context of the total deaths that might be expected had Covid-19 not existed. The way Covid-19 has been reported (alongside –and reinforcing- the lockdown itself) may have heightened fear but like the lockdown, itself this is a blunt instrument.

With regard to Covid-19, as with much else in life, risk is far from evenly distributed. Indeed the risk is marked by how uneven that distribution is-both geographically and between individuals. Certain health problems and characteristics are known to carry higher risks, even if the reasons why they do so may not yet be fully understood in all cases. At its most basic, the higher the number of risk factors somebody has, the higher their risk that Covid-19 will kill them.

Fortunately, for most people the risk is low, although even a very low risk when multiplied amongst millions of people, can still result in a disturbingly high number of deaths. The ONS reported of the deaths involving Covid-19 in March and April 2020 90.4% had at least one pre-existing condition. The mean number of pre-existing conditions was 2.7[4]. The main risk factors are:

- Age
- Obesity
- Heart Disease
- Black, Asian and minority ethnic (BAME)
- Diabetes
- Respiratory Disease –such as Chronic Obstructive Pulmonary Disease (COPD)
- Immuno-compromised patients –such as those receiving cancer treatment
- Chronic Kidney Disease (CKD)
- Deprivation

The risk to individuals from Covid 19 is far from uniform. In fact, it is highly granular. Both the incidence and effect of Covid-19 is distributed unequally across society. As a general rule, those who least can afford it, (both physically and economically) are hardest hit by Covid-19.

Whilst age remains the biggest risk factor, with people aged 80 plus being 70 times morel likely to die than those under 40, some groups (and occupations) are at much higher risk of catching and dying from Covid-19 than others, primarily due to age, gender, comorbidities, ethnicity and socio economic deprivation. Britain's ethnic minorities are more at risk. For example, controlling for age, poverty and other factors, people of Bangladeshi origin diagnosed with Covid19 are twice as likely to die of it as others and those of Pakistani origin, 1.4 times more likely.

The mortality rate amongst NHS and care workers has been significantly higher amongst the BAME personnel than the percentage they make up of the overall workforce. The Public Health England review as to why Covid-19 has had a disproportionate effect on people from ethnic minorities was poorly received – in part because it appeared to ignore the responses from the more than 1,000 organisations and individuals who supplied evidence for the review and partly from the absence of any action plan.

Deaths from Covid-19 are also more likely amongst men than women. ONS report[4] that the age standardised mortality rate (ASMR) in Wales is 630.6 per 100k for men compared to 363.2 per 100k for women. The difference is even higher in England (781.9 for men versus 439 for women) and this is a variable which has produced a lot of speculation as to its cause(s) but as yet no definitive explanation.

This is consistent with initial reports from China which found a higher mortality amongst men, but also with patients with a history of respiratory disease. At that time some commentators thought that Covid-19 would not be so severe in Europe (for

example) because China has a much higher percentage of the population who smoke (and who subsequently suffer from the likes of COPD) than is now the case in the likes of Europe and the USA

That optimism has not been borne out by events. This has spawned its own explanations. In particular the finger is pointed at obesity as a prime suspect in raised mortality risk. China has a much lower percentage of its population classified as obese, than European countries, whilst the USA is ranked 12th in the world with 36.2% of the population judged obese[5]. Subsequently, (and confusingly) there has even been speculation that smoking might even carry a benefit with regard to Covid-19 transmission and severity of symptoms!

Whilst the extensive research being undertaken worldwide may well quickly generate conclusive answers to these questions (such that parts of this paper may require revision as further evidence becomes available) it also has to be noted that a number of countries reported deaths look highly dubious (mainly because they appear to have suffered so few deaths compared to economically developed countries with what are typically considered robust public health reporting mechanisms. These include, the reported positions for China, Russia, and many 'second and third world countries' with poorly resourced health and welfare systems. In contrast, Belgium currently has the highest reported deaths per 100,000 population in the world (79 per 100k), and Belgium was unlikely to have been on any 'experts' list of countries that would be most severely affected at the outset of this pandemic.

There is a strong suspicion that some countries are under-reporting for political reasons and that they have the ability to control the flow of public information to do so. Others may simply not know their true death rate.

In terms of the latter we have already noted that it is not as simple to attribute deaths to Covid-19 (versus anything else) as people may initially assume. It is understandable that many people think that the recording of deaths internationally is undertaken in a consistent way, however that is not the case. In relation to Covid-19 the UK allows the death certificate to show Covid-19 as both the primary cause and a contributory factor. Some countries will also assign Covid-19 deaths this way, whilst others will restrict it to being the prime cause only. In some countries that will be narrowed further to those cases where Covid-19 was confirmed via testing. The result is people think they are comparing apples with apples, but a closer inspection shows that this is not the case.

The difference on the absolute number of deaths between countries is often the subject of media reporting (a figure providing limited informational content given the significant differences in population size, density and composition across the world). For example, England has one of the highest population densities in Europe and population density and places that are significant travel hubs are very strong predictors of high infection rates/fatalities. In relation to this it is worth noting that in 2019, a staggering 80.9m passengers travelled through Heathrow.

Reporting of deaths on a daily basis by the media tends to degenerate into a 'league table' approach, but that analogy is useful in relation to the length of time that will need to elapse before we can ascertain for certain which countries and regions have come out of this better or worse. Indeed, this needs to take place over not one season but probably several years…or up to a point when an effective vaccine has been administered. There are a number of reasons for this, including the impacts of possible subsequent waves of the virus and whether and when herd immunity is achieved. There is also a time lag in relation to assessing the full impact of excess deaths, both caused directly by Covid-19, or impacted by it. With regard to the latter, this will be a long list, including deaths caused by a reduction in cancer screening, non-presentation of life threatening illnesses, delays to treatments and suicides. With the former we have yet to see what the long term effects on those who became seriously ill with Covid-19 (but survived) will be-including those who were unfortunate enough to end up requiring mechanical ventilation for an extended period of time.

How many Covid-19 cases are there?

Drawing any conclusions from Covid-19 deaths in relation to confirmed cases is even more problematic because of the widely different reporting and testing regimes in place across the world. We do know that a large number of people can catch Covid-19 and display very mild symptoms. Many countries only test (if they test at all) once a person presents with significant symptoms such as high temperature and persistent cough (often upon admission to hospital). In contrast, some countries – South Korea, New Zealand and Germany for example- have been able to adopt widespread testing, including of those who are suspected to have come into contact with an infected person. The word 'able' is used because many other countries, including Wales and the rest of the UK would like to have tested more of the population but did not have (and may still not have) the infrastructure and/or laboratory capacity currently in place to do so.

The more testing that is undertaken, the lower the confirmed case to death ratio will be (essentially the denominator is greater, the more confirmed cases that are found because most of these cases will fortunately NOT result in death). That explains the likes of Germany's very low cases to death ratio but not their absolute lower number of deaths. More useful is deaths per 100,000 population, but even then there are dangers in a snapshot approach (even if all deaths are being correctly reported). It is quite possible for a country to have a relatively high death rate initially, obtain herd immunity earlier and then see other countries death rates gradually climb to meet (and possibly exceed) theirs. There is speculation that this will be the case with Sweden (which currently has a death rate of 33 per 100,000 which is about three times that of Denmark and seven times that of Finland[5]. However we should also note that this is still considerably below the likes of the UK, France, Spain and Italy. Only time can tell who has been fortunate enough to escape the worst effects of the virus…and why.

In making that determination, Covid-19 mortality rates will be an important part of the equation…but not be the only one. There will also be the impact on deaths from

other causes, on morbidity, on services and support as well as the wider social, economic and environmental factors, all of which influence health and well-being. Will we see a sharp rise in mental health problems, suicides and preventable deaths from the likes of cancer and heart disease? Will we also see the impact of poverty and unemployment? Which economies will be least impacted by public health measures and which will subsequently recover quickest and most fully? There is a known relationship between population health and the 'health' of the economy. A country made poorer by its response to Covid-19 is very likely to also be a country that will see worse health outcomes. Furthermore, if tax revenues decline it becomes harder to fund public services such as the NHS.

Collating and communicating the information?

To produce this paper has required an element of detective work. Data, information and reports are not conveniently accessed from one organisation or by going to one website, but are spread (seemingly at random) across multiple agencies and websites. This can apply as much to finding information within the UK as it does accessing worldwide data. Neither professionals, nor or the public should be required to interpret such confusing information or act like detectives to find and make sense of Covid-19 related information. This disease feels like it has been with us for some time and it will certainly be a significant factor in our lives for considerably longer. More attention needs to be given how data/information is collected, collated and then effectively communicated.

At the moment many gaps in knowledge still remain for the public and professionals. One might assume that Welsh Government has access to significantly more data such as: How many staff are currently off sick? How many staff have been confirmed (via testing) to have had Covid-19? How many clinicians volunteered to re-join the workforce, and how many are now working? How many extra volunteers are there and what are they being used for? How much Personal Protection Equipment (PPE) do Welsh health and care organisations actually have in stock and/or still need? How much testing is happening, to whom and where? How many of the new Covid-19 cases that still being reported are being generated in hospitals and care homes versus the 'community'?

Finally, there is also the question of an entirely missing component in Wales' health reporting with regard to health and healthcare that is NOT Covid-19 related. These include cancer wait times, emergency care and elective care wait times and delayed transfers of care.

The decision to relax performance targets in Wales during the Covid-19 crisis can be defended. Not publishing the likes of cancer wait times or being able to see the impact on elective waiting times cannot. Attendances to A&E were down by a previously unthinkable 60% and emergency admissions down by 35%[7] but are slowly climbing back. The same applies to ambulance calls. Many will be surprised to hear that there have been as many as 2500 empty beds across NHS Wales and

60% of ITU beds also empty. As Covid-19 cases now only take up a small minority of hospital general and ITU beds (as of the 17th June there were only 33 Covid-19 cases in ITU and some 170 empty ITU beds, and 789 confirmed, recovering and suspected Covid-19 cases in general beds out of a current total bed capacity of C. 7800) the surge capacity that was created is being reduced. At one point there were around 8300 total beds in NHS Wales and over 400 ITU beds (there are now about 270)[7].

However we have no idea how any of the above has impacted on waiting times for services because they and many other reports, have been suspended in Wales. Whilst there is plenty of routine reporting across Welsh Government that can safely be suspended, when it comes to the impact of Covid-19 on our health service (and the public's health) we need more information, not less.

In order to address these matters we must ensure we have more consistent, open and easily accessible information, where possible through a single point of contact such as Public Health Wales and its Observatory, or Stats Wales. These need to be tailored to meet the needs of both professionals and the public. Reporting needs to be sound, reliable and timely and translated into simple concise messages to inform the public to help them play their part in supporting the necessary actions to help reduce the impact of Covid-19.We have previously made these points back in 2013[8] in 'Data Information in NHS Wales: The good, the bad and the ugly' and also in 2018[9] in 'Measuring Health Outcomes a complex system'

Covid-19 has presented many challenges, including ensuring that we have access to information that is reliable, fit for purpose and actively used to inform actions and plans. Whilst we, or others, don't have all the answers, the need to get basic information and its collection, collation and communication right, is an essential role. The national public health agencies should be proactive in this; not just now but as a core and fundamental part of their ongoing work and role.

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