

Opinion: Why 'Patient Zero' is such a toxic term

April 2 2020, by Richard McKay



Mary Mallon, a 'healthy carrier' for typhoid fever, in hospital, 1909. Credit: Wikimedia Commons

Heightened fears surrounding COVID-19 have once again brought the

idea of "patient zero" into public consciousness. Ever since it was coined by accident in the 1980s, this popular yet slippery term has regularly—and misguidedly—been applied to infectious disease outbreaks and public health efforts to control them.

Steve Wozniak, co-founder of Apple, [tweeted earlier this month](#) that he and his wife might be "patient zero" for the epidemic of COVID-19 in the US after they returned from a trip to China with symptoms. He later described his use of the phrase as ["kind of a joke"](#).

Less frivolously, "the hunt for patient zero" formed part of a recent [BMJ headline](#) for an editorial examining the devastating epidemic unfolding in Italy. The piece described local attempts to find the country's initial coronavirus cases, hypothesising that they might be a pair of visitors from China's Wuhan region, where [health authorities](#) were confronting the world's earliest recognised large-scale outbreak.

Amid heightened [contact-tracing](#) efforts to locate cases linked to a doctor in the UK who was displaying symptoms of the infection, the Daily Mail used similarly dramatic language. [An article](#) described "the desperate hunt ... for an unknown coronavirus spreader" who "gave"—note the implied volition of this word—"the deadly illness to the UK's 20th victim—the first Briton to catch it in the country."

And even more recently, the Mail on Sunday followed news of prime minister Boris Johnson's positive COVID-19 test result by publishing a two-page spread asking its readers: ["DID BARNIER INFECT BOJO?"](#) With little evidence, the authors intimated that Michel Barnier, the chief negotiator for the EU, "might be the 'Patient Zero' who brought [the] virus to No 10," representing "the ultimate revenge for Brexit."

With the words "patient zero," you have a distinctly catchy phrase. This was the reason Randy Shilts, the American journalist [whose work on the](#)

[AIDS epidemic](#) initially amplified the term, [adopted it in the first place](#). It sounds scientific, and as if it signifies the absolute beginning of an epidemic. It shares a linguistic link to 20th-century military expressions such as ["zero hour"](#) (when an action begins) and ["ground zero"](#) (the point below where a bomb detonates), so it conveys a sense of excitement too.

But apart from its attention-grabbing tone, the phrase is hopelessly confusing. Its lack of precision and accidental formation disqualify it from formal usage, so most researchers will not touch it. And stories about unknown disease "spreaders" triggering a "desperate hunt," whether or not they explicitly refer to a "patient zero," are frequently giving expression to communal fears about dangerously reckless behaviour. On the surface, these stories seem motivated by science. Scratch a little deeper, though, and you will often uncover a desire to assign blame.

We should abandon the toxic phrase "patient zero" and discuss contact tracing—the process of locating individuals who have crossed paths with people who are infectious—with great care. Otherwise, we risk increased confusion, scapegoating and under-emphasising the significance of asymptomatic cases. These are all things which are deeply unhelpful for our collective response to COVID-19.

Confusion

First, let's tackle the confusion raised by the term itself. "Patient zero" is often used interchangeably for three different scenarios: first case *noticed*, first case *here*, and first case *ever*. While there are legitimate reasons for discussing each of these situations, better terminology exists for doing so.

Speaking of "cases" instead of "patients" allows us to be more specific. By doing so we include those who may be infected and infectious but

who don't acquire official "patient" status by seeking treatment.

In terms of "first case noticed," since at least the 1930s, health investigators engaging in contact-tracing work have used the phrase "index case" to mark the first person in a household or community whose symptoms grabbed their attention. [Researchers studying tuberculosis](#) in Tennessee during the Great Depression defined "index case" as "that person through whom attention was drawn to the household."

Crucially, these same researchers were quick to emphasise that this person might not be "the initial case in the household in point of time." Turning our thoughts to COVID-19, there are many reasons why this might hold true. An initial case whose symptoms were so mild that she did not seek assistance. A child who picked up the infection first but took longer than his siblings to develop a fever. Or perhaps a grandparent with all the signs of infection, but without medical insurance and afraid to seek treatment.

The Tennessee tuberculosis researchers also pointed out that the index case might not be a true case of disease at all. Someone might appear to be ill, draw attention to a household, but ultimately test negative for tuberculosis.

To refer to "the initial case ... in point of time," epidemiologists coined the phrase "[primary case](#)". In understanding how a disease might spread through a household or community, it can be useful to know who was the primary case *here*, in a particular location. By knowing when this person was infectious and by tracing their movements through a community, investigators can identify other people who might be at risk of infection and, ideally, test and treat them.

Where epidemiology lacks a good alternative phrase is for the first

person *ever* to become infected. ["Patient zero" often springs up](#) to fill this void in informal discussions.

There are many reasons why this person, the first human case ever in a particular outbreak, is seldom located: the absence of recognisable symptoms, gaps in disease surveillance, delays in recognising an outbreak, lack of effective testing. In some cases, the person [popularly and arbitrarily crowned as "patient zero"](#) may simply be the person with a positive test result whose likely date of infection is the [earliest on record](#).

As such, any purported "first case ever" is largely figurative. Lacking a better phrase, we might choose to call this person the "alpha case" or "ur-case," or, for infections such as HIV or COVID-19 where a virus transfers from an animal host to humans, the "crossover case." "Crossover case" is readily understood. And "alpha" and "ur" are two words commonly used to describe absolute beginnings, each also hinting, appropriately, at a mythical realm ("In the beginning...").

Each of these designations is meaningful. Index cases are helpful in terms of seeing how disease comes to authorities' attention ("index" literally meaning "that which serves to point"). Primary cases are useful in terms of organising the key elements of epidemiology – [time, place and person](#) – into a narrative chronology that helps bring order to the complexity of rapidly accumulating data during a health crisis.

Likewise, it can be important to talk of crossover cases—even if they are seldom directly identifiable. Understanding their habits and living conditions might reveal risks that can be avoided in the future. Studying how a virus has evolved over time from its first interactions with humans can offer insight into its past trajectory as well as possible future points of intervention for treatment and vaccine research.

In short, each of these situations is worth discussing with precision. With its many possible meanings, "patient zero" is simply not up to the task.

Blame and scapegoating

Identifying a "patient zero" is also rife with potential to incite blame and scapegoating. To understand how, it's useful to think historically about the overlapping but divergent interests of two different groups keenly following the spread of infection during an epidemic: members of the public and public health workers.

[Long before](#) they had the ability to test for specific germs, those studying epidemics—whether religious, civic or medical authorities—found value in locating the first cases. Like now, they were keen to work out what identifiable factors might have led to ill health in the community.

Many medieval Europeans believed that disease could spring up from dangerous miasmatic air. From the 14th century onward, conspiracies also circulated about specific minorities—lepers, Jews, heretics and sodomites—causing the plague, either directly by poisoning wells, or more generally by provoking God's punishment with their behaviour. Members of minority groups who were judged to have disobeyed community standards often faced isolation, banishment and sometimes death in the aim of seeking atonement.

Humans are storytellers, and through several centuries of epidemics in Europe and North America (where my research has focused) they have told stories of how outbreaks started and spread. These included tales of how foreign travellers brought non-native disease (the malady from X country) – a phenomenon later aptly described in relation to AIDS as a ["geography of blame"](#).



Gaétan Dugas, photographed by Ray Redford in Vancouver, 1972, before becoming the prototypical 'patient zero'. Credit: Richard McKay, Author provided

On a more local level, observers also described real and fictional chains

of disease transmission between named people ("Our town was free from infection until so-and-so came"; or "A infected B with the pox, who infected C and D"). With their similarity to family trees, I call this second kind of story a ["genealogy of blame"](#).

Both types of stories tend to feature people behaving inappropriately, immorally or wickedly, especially by transgressing important boundaries. These might be natural, religious or geographic divides. One finds examples of proposed "ur-cases" of the pox generated by crossed celestial bodies, crossed species or crossed borders.

These ancient and widespread stories that explain disease and misfortune link to the popular stories of a "patient zero" still told today. They trace real or perceived connections between different people to understand how illness spreads. But unlike the main motivation of public-health contact tracing, a much more recent practice, these stories enact personal distancing through words, aiming to provide reassurance by locating the responsibility for disease elsewhere.

Contact tracing as we now define it [developed in the late 19th and early 20th centuries](#) when investigators and health departments drew upon the remarkable discoveries of bacteriological researchers and applied them to public health problems. Scientists had developed new techniques that allowed them to identify specific germs as the cause of specific diseases. This powerful breakthrough in studying infection, in turn, gave health authorities a much better understanding of how a specific germ was moving through a population and where to allocate resources for prevention.

For diseases such as typhoid fever, tuberculosis, syphilis and gonorrhoea, investigators could now identify potential cases with more confidence. Increasingly, public health workers tested these cases to see if they were carrying specific germs, followed up their contacts, and then applied

measures such as treatment, quarantine or isolation to prevent further spread.

The most famous instance of these tools being put to use was with typhoid fever and the [case of Mary Mallon in early 20th-century New York](#). Authorities found this Irish American cook to be a "healthy carrier"—capable of infecting others while remaining symptom-free herself—and they advised her against continuing to work as a cook. When they later traced numerous infections and two deaths to a maternity hospital where Mallon had resumed cooking, she was forcibly confined to North Brother Island for more than two decades until her death in 1938.

In carrying out their responsibilities, public health workers have long benefited from media stories that borrowed heavily from crime fiction, portraying them as tireless "[disease detectives](#)". Alexander Langmuir, the godfather of the Epidemic Intelligence Service at the US Centers for Disease Control, [actively cultivated such media accounts](#) of his organisation's epidemiologists from the mid-20th century onward.

One downside, however, to this popular public image is the overlap in word choices and story conventions drawn from crime fiction. Describing public health workers as "disease detectives" opens the door to characterising the contact-tracing process as a "hunt" for guilty "suspects," people who choose to "give" their infections to innocent "victims" (another harmful story formula with a long history). This is especially troubling if the people in question are going about their lives without the knowledge that they are infected.

It is obvious that a public health method that investigates the same person-to-person connections that have long fascinated members of the public will be particularly vulnerable to mixed messages like these. As a result, writing about contact tracing in relation to a public health

emergency must always be done with extreme care. Word choice matters.

Journalists focusing on a "patient zero" risk invoking widespread and historically rooted social impulses to attribute responsibility and blame to the people linked to chains of infection. On their side, public health workers might think twice about using the term "superspreader." This evocative and stigmatising phrase, still in relatively wide use, describes an infected person who transmits an infection to many others, and [has often been applied](#) to the first-ever "patient zero": Gaétan Dugas.

What we don't see

Many people will know the story of Gaétan Dugas, the French-Canadian flight attendant [wrongly accused](#) of being "patient zero" of the North American AIDS epidemic. Briefly, this man emerged as a person of interest in 1982 when American public health investigators received reports that a number of gay men with AIDS in California had had sex with one another. This was before a virus was known to be the cause and before a test was available to determine who was sick.

In the absence of a definitive test for AIDS, this sexual network of cases, all of which fit the narrowly defined official case definition for the new syndrome, offered an opportunity to study whether the syndrome was caused by a sexually transmissible agent. The Canadian appeared to provide the sexual link to several Californian cases that otherwise did not have any apparent connection. He was labelled the "out of California" case because he lived outside of the state, and "case O" or "patient O" for short.

The investigators' detailed contact-tracing work revealed a web of sexual connections, eventually linking cases in California with others in New York and cities in other states. The [investigators initially represented this](#)

[network](#) with "patient O" at the centre. After other researchers later misread the letter O for the numeral 0, many began to misinterpret the person at the centre of the diagram as "[patient zero](#)", the "primary case" for the North American epidemic.

This example has [received more attention recently](#) for the personal consequences it had for Dugas's memory and the pain it brought his loved ones, as well as for the stigmatising story frame that it set up for subsequent "patients zero." Initially, Randy Shilts's popularising account, *And the Band Played On*, even emphasised—using dubious evidence—that Dugas's refusal to heed public health guidance demonstrated that he was intent on deliberately infecting others.

However, this historical example also offers a useful cautionary tale for thinking about identifiable individuals linked to a cluster of infections, and about asymptomatic cases more generally.

Dugas, the prototypical "patient zero," did have a very large number of sexual contacts, and some of the connections depicted took place before his symptoms became apparent. But several other men with AIDS represented in the same diagram had as many or more sexual partners. The main difference was that they could not, or would not, share the contact details for their partners in the way that the cooperative Dugas did. The result was that while Dugas's identified sexual partners radiated out from him in the diagram like spokes on a wheel, these other men were surrounded by empty space.

In this way, the limits of a contact-tracing model focusing on identifiable cases become clear. When we represent something visually, it becomes much easier to focus on what is depicted instead of what might be missing. Similarly, by representing the known connections between people with symptoms, we risk overlooking the just-as-important connections between those who are infectious but symptom free, and

who are less likely to be linked to a chain of infection.

There is another way we can now understand the cluster diagram to direct our attention away from what is important. In 1982, it was reasonable to hypothesise that it might only be a few months between someone being exposed to whatever caused AIDS and subsequently displaying signs of the disease. Representing these men's sexual connections in a diagram made sense because it seemed likely that these depicted exposures were the ones that had permitted a transmissible agent to infect them.

But it became increasingly apparent that it took much longer for people to display symptoms after they were infected, a process which we now understand to be in the order of eight to ten years, in the absence of other health issues. And we now know that by the time that investigations into AIDS began in earnest in 1981, many thousands of Americans were already infected, going about their lives without realising they had acquired a virus that they were transmitting to other people.

So, [by the late 1980s](#), and certainly from our current viewpoint, it is clear that most if not all of the sexual connections depicted in the cluster diagram were *not* the acts of sexual activity that led to these men becoming HIV-positive. Those exposures would have occurred years earlier, in the early to mid-1970s, beyond the focus of the investigation and therefore left out of the diagram. Not only does this further remove any particular significance attributable to Dugas, but it also importantly reminds us of what we too may be failing to see from our own limited present-day perspective.

In short, by focusing too much of our attention on a "patient zero" or the cases uncovered in a contact-tracing investigation, we risk diverting our attention from the hazards posed by infectious people without

symptoms. Also, if we spend too much time thinking about individuals, we risk overlooking steps we can undertake together in our communities.

In other words, the more we can do to think of infection being *here* among *us*, instead of *over there* among *them*, the more it will allow us to focus on behaviours—things like hand-washing, self-isolation and physical distancing—that can collectively reduce our risk of infection *now*.

Contact tracing will, and should, remain a vital part of the response to COVID-19 for many months to come.

Since public health responses to a global pandemic generally fall within national jurisdictions, it makes sense that a country's health authorities will give heightened attention to the first cases of a disease recognised within its borders. Yet authorities should remember that some will interpret this attention as an encouragement to blame outsiders for the disease, feeding into long histories of viewing other parts of the world as disease incubators.

In locations where the virus has not yet become apparent, vigorous tracing of new cases and testing their contacts in a bid for "containment" can help prevent a shift to undetected "community spread." And in areas where the virus is widespread and the population has been subjected to restrictive measures, any relaxing of controls will also require the careful investigation of new cases to avoid a re-escalation of infections.

Regardless, there should be no more "patient zero" in our stories of COVID-19. We must be conscious of the stories we tell and the connections we trace, remaining mindful of the ripple effects these can have. Writing of a "patient zero" is a damaging red herring that distracts from constructive efforts to contain the epidemic. Let's wash our hands of this toxic phrase. Our general health, and our ability to understand

epidemics now and in the future, will be stronger as a result.

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Provided by The Conversation

Citation: Opinion: Why 'Patient Zero' is such a toxic term (2020, April 2) retrieved 5 May 2024 from <https://medicalxpress.com/news/2020-04-opinion-patient-toxic-term.html>

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