# ilc...

## Painfully unaware

Improving older people's understanding of shingles vaccination in an ageing society

Health and care Inequalities International Prevention Life expectancy Disease and Conditions

## Acknowledgements

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## **Executive summary**

Vaccination is a proven preventative method for protecting older people against shingles. However, across Europe, knowledge and awareness of the disease is poor and vaccination uptake is low.

The virus that causes shingles and chickenpox costs the EU €660 million per year. For older patients, medical treatment costs England an average of £445 per case. There's a clear case to encourage preventative treatment rather than curative treatments, for the benefit of both individuals and families, and the wider economy.

In a survey that covered thousands of people aged 50 and over in nine European countries – Austria, Belgium, France, Greece, Italy, the Netherlands, Spain, Sweden, and the UK – we found that:

- While adult vaccination is important, shingles vaccination has fallen through the cracks:
  - Nearly eight out of ten of participants agree that vaccination is important to their health as they get older.
  - Most have heard of more common vaccinations, like flu or COVID-19, but only 42% are aware of the shingles vaccination.
  - Less than 10% had received the shingles vaccine.
- Knowledge of shingles is poor:
  - 6% of all participants have never heard of shingles, with substantially higher figures in Spain (18%) and Belgium (20%).
  - Over half don't know the age groups at greatest risk from shingles, and 15% think they will never be at risk.
  - One in five don't know how severe a shingles infection can be.
  - Knowledge was better in countries with stronger shingles vaccination programmes and/or higher health literacy.
  - Participants from countries with higher shingles vaccination uptake more often have better levels of knowledge about the disease.

- Some healthcare professionals aren't warning patients about the risk of shingles:
  - Only one in ten of our participants have been informed about the risk shingles poses to their health by their doctor; in Sweden and the Netherlands, this number is as low as one in twenty.
  - There's a strong positive correlation between uptake and communication from a healthcare professional about the risks of shingles.
- Knowledge is the biggest motivator for participants who had already been vaccinated:
  - Uptake is driven by either understanding how shingles can affect one's health or knowing someone personally who has had shingles.
  - Other drivers for vaccinating include: free vaccination, a convenient point of vaccination, an easy vaccination process, or being offered the vaccine on the spot during a medical appointment.
  - Participants from countries with weaker vaccination programmes are more motivated to vaccinate if they know someone who has had shingles.
- Free vaccination and improved knowledge would support increased uptake:
  - Over one in four participants who haven't been vaccinated say better knowledge of the consequences of shingles would encourage them to get vaccinated.
  - One in four say free vaccination would encourage them to get vaccinated.
  - 90% of participants that know about shingles are interested in getting vaccinated.

## **Our recommendations**

#### Investing in systems designed for prevention:

- EU member states and the UK should have a clear target to vaccinate 75% of the eligible population against shingles.
- Every country should officially recommend the shingles vaccine for older and immunocompromised individuals.
- Vaccination should be fully funded.
- The vaccination process should be easy and streamlined, possibly by:
  - vaccination piggybacking
  - ° offering the vaccine on the spot in medical appointments
  - removing barriers like the requirement for a prescription

#### Actions to inspire and engage:

- Every country should have comprehensive communication campaigns to encourage uptake, which could include:
  - call-and-recall programmes for those of eligible age
  - shingles birthday cards
  - ° representative campaigns that leverage personal stories
- Healthcare providers should actively inform patients about the risk of shingles and encourage vaccination uptake.
  - Programmes or initiatives that encourage healthcare workers to proactively converse with their patients about shingles and offer the vaccine are vital.
- Governments and healthcare professionals should also work with trusted community organisations to further encourage the dissemination of information and uptake of vaccination.
  - This not only addresses vaccine hesitancy and vaccine inequity, but also takes some pressure off overworked, under-resourced healthcare systems.

#### Actions to democratise access to prevention:

- Vaccination should be made more widely available in various healthcare settings in addition to GP surgeries, including pharmacies, workplaces and other community areas.
- Resources and access must be equitably distributed across regions within countries, with each country ensuring an adequate and equitable allocation of funds based on regional needs.

#### Actions to support the effective use of technology:

- Governments and healthcare systems should ensure that reporting and data collection is more comprehensive and is required at regional, country and European levels.
  - This data tracking should include rates of infection, vaccinations and regional hotspots, as well as who is fully vaccinated and who still needs to be protected.
- To ensure consistency, healthcare systems should implement automated reminder services for healthcare professionals that remind them to recommend and encourage vaccination when eligible individuals have appointments for other issues.

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## Introduction

Over 20% of people in the EU are aged 65 or older; this figure is expected to increase to 30% by 2100.<sup>1</sup> This rapid increase makes it vital to support people and help them to age in good health. Prioritising healthy ageing will not only see more people living longer lives but will offer economic and social improvements for individuals and the wider community. When older people remain in good health, they need less medical support, can continue to work for longer, and support the economy by contributing to their savings and spending money.<sup>2</sup>

The virus that causes shingles and chickenpox costs the EU €660 million per year.<sup>3</sup> For older patients, medical treatment costs England an average of £445 per case.<sup>4</sup> There's a clear case to encourage preventative treatment rather than curative treatments, for the benefit of both individuals and families, and the wider economy.

### Vaccination

Vaccination is one of the foundations of healthy ageing. Its benefits are consistently exemplified in the limiting or eradication of diseases and protection of vulnerable populations.<sup>5</sup> Global vaccination efforts allowed smallpox to be completely eradicated by 1980.<sup>6</sup> The COVID-19 pandemic and its subsequent vaccination programmes have illustrated this again: in the UK alone, COVID-19 vaccination saved the lives of over 10,000 older people in 2021.<sup>7</sup> Across Europe, the estimated number of prevented deaths in people aged 60 and older was almost 470,000.<sup>8</sup>

Despite the clear benefits of vaccination, we still see various barriers to uptake, such as vaccine hesitancy from individuals and inadequate communication from governments and public health organisations. Barring the COVID-19 and influenza (flu) vaccines, adult immunisation rates remain low in Europe.

Few European countries have ever met the World Health Organisation's (WHO) annual target of vaccinating 75% of the population aged 65 years and older against the flu.<sup>9</sup> Uptake and coverage for other recommended adult immunisations, such as shingles, are consistently low worldwide. This is regardless of social determinants like race, economic status or geographic location.<sup>10, 11</sup> Previous ILC research has shown pneumococcal vaccination coverage in older people sits at just over 24% across Europe.<sup>12</sup>

#### Awareness

One in every three adults will get shingles at least once in their lifetime.<sup>13</sup> The illness disproportionately affects older people, presenting with painful symptoms and life-changing, long-term complications that can include hearing loss, loss of vision and chronic pain.<sup>14, 15, 16</sup> The shingles vaccine is a key prevention tool, but lack of awareness and the high cost of treatment mean vaccination coverage in Europe is extremely low.<sup>17</sup>

Public awareness of shingles remains limited across Europe, and sparse vaccination programmes aren't improving uptake. In the International Federation of Ageing's EU-based report,<sup>18</sup> lack of knowledge about the shingles vaccine, and the importance of adult vaccination in general, was credited as a major cause of low coverage across Europe. A recent UK study showed that not only do eligible adults lack knowledge of shingles and vaccination, but that around 56% of GPs were unaware of shingles communication campaigns. As a result, they weren't recommending vaccination to eligible patients regularly. If we are to increase vaccination uptake, we must rely on healthcare providers to inform and encourage patients to vaccinate.<sup>19</sup>

For this study, we surveyed 3,613 people aged 50 and over, living in nine European countries: Austria, Belgium, France, Greece, Italy, the Netherlands, Spain, Sweden and the UK. Our aim was to better understand attitudes towards shingles and the shingles vaccination, and the role that state support and funding can play in improving vaccination uptake.

#### What is shingles?

Shingles and chickenpox are both caused by the varicella-zoster virus (VZV). After a chickenpox infection, VZV lies dormant in nerve cell bodies around the brain and spine. It can later reactivate to cause shingles. It's not fully understood what triggers this reactivation, but it's likely to be linked to a decline in the immune system's ability to control the virus. This means that shingles is more common, and often more severe, in older and immunocompromised people.<sup>20</sup>

The first symptoms of shingles is usually headaches and an uncomfortable tingling feeling on specific areas of the skin. Shortly after, a painful rash occurs on one side of the face or body, most commonly on the chest or abdomen. This rash turns into sore, fluid-filled blisters and can take around four weeks to heal.<sup>21</sup> Further complications of shingles include:

- vision loss from blisters in or around the eye<sup>22</sup>
- hearing loss, tinnitus, vertigo, facial paralysis or loss of taste from blisters in or around the ear<sup>23</sup>
- open blisters becoming infected
- neurological conditions like encephalitis and meningitis which can be fatal or lead to long-term problems like epilepsy or paralysis
- postherpetic neuralgia (PHN), or long-term debilitating nerve pain<sup>24</sup>

In a small number of cases, infected patients can present without a rash but with other complications, making shingles difficult to diagnose.<sup>25, 26</sup>

## The impact of shingles

In Europe, approximately 95% of the adult population carries VZV. Around one in three adults will develop shingles at some point in their life. The likelihood of developing shingles increases with age, which means that as Europe's population grows older, we're more likely to cases increase.<sup>27</sup> As we age, our immune systems weaken, making us more susceptible to severe cases of shingles that require aggressive treatment plans. Additionally, older people are more likely to suffer from increasingly severe side-effects and complications. The risk of PHN for patients aged less than 50 is 2%, but for those aged 50 and over it increases to 20%, and over the age of 80 it increases to 35%.<sup>28</sup> As detailed above, many shingles complications can be extreme and involve additional medications and therapies, which increases the overall cost of treatment.

Despite its prevalence, public awareness of shingles is relatively low, with cases often going unreported.<sup>29</sup> In the context of an ageing European population, it's important to raise awareness about shingles and its potential complications. Older people with noncommunicable diseases are at an even higher risk of developing shingles and experiencing heightened side effects. It's estimated that one in four Europeans live with two or more chronic conditions,<sup>30</sup> meaning millions of people are at risk of a severe shingles infection.

The economic impact and individual burden of shingles can be substantial, placing a significant burden on healthcare systems. In England alone, treating shingles in younger people is estimated to cost between £104 and £189 per case, while the cost for older patients can range from £401 to £507 per case.<sup>31</sup>

Across Europe, costs associated with VZV<sup>a</sup> are estimated at €660 million per year. About €230 million of this is related to direct treatment costs, while €430 million relates to indirect losses. The greatest associated indirect cost is work loss, where infected individuals or caretakers of those affected are unable to work.<sup>32</sup> Other indirect costs include ongoing treatment for lasting complications, mental health care after the shingles infection has cleared, and transportation to receive treatment.<sup>33</sup> Deaths from VZV also present a further indirect cost of €21.9 million a year.<sup>34</sup>

## Vaccine availability and recommendations

In 2013, Europe's first national shingles immunisation programme was rolled out in the UK.<sup>35</sup> National programmes were subsequently established in other European countries, including Greece, Spain, and Italy. However, most European countries either have no official recommendations, or recommend vaccination but don't subsidise its cost.<sup>36</sup>

<sup>&</sup>lt;sup>a</sup>These are costs from both illnesses caused by VZV: shingles and chickenpox, as there's no data available on the economic impact of shingles alone.

## Table 1: Shingles vaccination recommendations in nine European countries

| Country               | Recommended age: July 2023 <sup>b</sup>   | State<br>funding |
|-----------------------|---|------------------|
| Austria <sup>37</sup> | 50+   | No               |
| Belgium <sup>38</sup> | 50+   | No               |
| France <sup>39</sup>  | 65-74   | Yes              |
| Greece40              | 18-64 if immunocompromised<br>65+   | Yes              |
| Italy <sup>41</sup>   | 50-64 if immunocompromised<br>65+<br>[some differentiation across regions]          | Yes              |
| Netherlands42         | 18-49 if immunocompromised<br>60+   | Partial          |
| Spain <sup>43</sup>   | 50-64 if immunocompromised<br>65+<br>[some differentiation across regions]          | Partial          |
| Sweden <sup>44</sup>  | No official recommendation – currently investigating including one in national plan |                  |
| UK <sup>45</sup>      | 70-79   | Yes              |

## **Classification of vaccination programmes**

It's useful to distinguish between the 'stronger' vaccination programmes, which facilitate and encourage increased uptake, and 'weaker' programmes that leave significant gaps where patients are likely to miss out on immunisation.

Based on the recommendations as of July 2023, this study. classifies those in the UK, Greece and Italy as 'strong' programmes. The cost of vaccination is fully funded by these national health services at the point of access. Free vaccination is easily accessible in doctors' surgeries, as well as pharmacies in the case of Greece and Italy.

<sup>&</sup>lt;sup>b</sup>The survey on which this study is based was administered in July 2023. Between data collection and publication, some country recommendations have change. These updated recommendations can be found in Appendix 1.

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'Semi-strong' vaccination programmes include those in France and Spain, which have strong aspects, along with weaknesses that limit vaccine accessibility. Although Spain has a strong vaccination programme and good attitudes towards vaccination, it has a lower uptake. The decentralised regional healthcare system results in differences in recommendations and vaccine availability. In France, vaccines are easily accessible in community pharmacies and are free at point of access, but an individual requires a prescription from their GP before they can receive the vaccine.

The programmes that we classify as 'weak' are those in Belgium, the Netherlands, Austria and Sweden. Belgium has no government funding, and a convoluted process for accessing vaccination: for a shingles vaccination, you must go to the doctor, collect a prescription, collect the vaccine from the pharmacy, and then return to the doctor to have it administered. In the Netherlands, vaccination is only funded for severely immunocompromised people. The Dutch recommendation is relatively new, and awareness is low. Austria has the same issue, with low awareness of the recommendation and poor communication from its healthcare sector. Sweden has no official recommendations, making it the weakest of all.

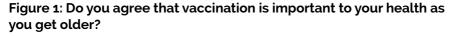
| Strong      | Greece, Italy and the UK                      |
|-------------|---|
| Semi-strong | France and Spain                              |
| Weak        | Austria, Belgium, the Netherlands, and Sweden |

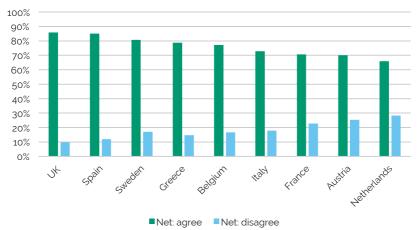
## Attitudes towards vaccination

- Nearly 8 out of 10 participants agree that vaccination is important to them.
- COVID-19 and flu are the best-known vaccines across all countries.
- Only 42% of participants know about the shingles vaccine, and only 8% have received it.

## How important is vaccination to Europeans?

In each country, the majority of participants agree that vaccination is important to their health as they get older.





Generally, participants from countries with stronger adult vaccination programmes tend to have higher levels of agreement: this includes Greece, Spain, Sweden and the UK. Spain (85% of participants) and the UK (86%) have the highest levels of agreement, along with strong adult vaccination programmes. Spain has consistently low levels of vaccine hesitancy, and a high level of public trust in national healthcare systems.<sup>46</sup> A 2020 study by the European Commission (EC) found that Spain and Portugal had the highest level of vaccine confidence across the EU and UK.<sup>47</sup>

#### Why Spain's trust in vaccination is so high

One reason why Spain's level of trust and vaccine acceptance is high can be attributed to its relatively late introduction of democracy in 1975, following the end of the Francoist dictatorship. Franco's government invested little in public health and failed to prioritise vaccination. This means that many remember the terrible impact polio had on Spanish citizens.

From the mid-1950s, two polio vaccines were rolled out in most other European countries, but this wasn't the case in Spain, resulting in thousands of deaths and disabilities. When Spain created and rolled out a modern public health system and vaccination schedule in the 1980s, the Spanish people understood the difference it made to overall health and reduced disease rates. Spanish public health authorities also work hard to refute vaccination-related conspiracy theories, which also contributes to low levels of vaccine hesitancy.<sup>48</sup> But future generations won't have the same opportunity to remember the positive impact of vaccination. It's possible that vaccine complacency may become more widespread as fewer people personally remember the impact of vaccination.

The UK also has high levels of vaccination confidence and trust in the public health system. In the same EC study, the UK ranked fifth for vaccine confidence.<sup>49</sup> British people consider the NHS to be the most trusted public service in the country.<sup>50</sup> Free healthcare at the point of delivery, high-quality care, and transparency and accountability all contribute to this level of trust despite current burdens on the NHS.<sup>51</sup> The UK has historically high vaccination rates; it's one of only two European countries that has ever managed to comply with the WHO recommendation to vaccinate 75% of older people against the flu. It's also the only country to achieve this target in any year since 2010.

The Netherlands is the one other country to have achieved this in the early 2000s, but uptake has steadily decreased since 2008.<sup>52</sup> In fact, participants from the Netherlands had the lowest level of agreement on the importance of vaccination (66%), and the highest level of disagreement (28%). This is in line with its current vaccination trends. Dutch citizens are less likely than other Europeans to believe that vaccination is important, safe, and effective:<sup>53</sup> their belief in these qualities has been declining steadily over recent years. There have also been decreases in the uptake of infant vaccination, MMR vaccination in school children, and HPV vaccination for teens.<sup>54</sup> But overall, vaccination is clearly important to the majority of Europeans, suggesting an understanding of the value it has throughout people's lives. On the other hand, we can see substantial variation between countries in awareness of different vaccinations, and more importantly, in uptake.

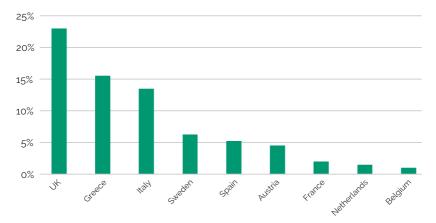
## Where does shingles fit into European's vaccination priorities?

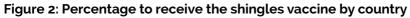
We asked participants whether they had heard of a variety of vaccines, and which vaccinations they had received. Flu and COVID-19 are the best-known and have with the highest uptake.

Flu is a common illness, and vaccination is widely recommended by healthcare professionals around the world. It's also a seasonal vaccine, which means that annual vaccination programmes increase awareness. As one the oldest vaccines in existence, having been created in 1938, it's understandable that it's better known.<sup>55</sup> 59% of our participants have received the flu vaccine.

The severity of the COVID-19 pandemic and the international push for vaccination has made uptake for this vaccination even greater, at 85% of participants.

On the other hand, awareness of shingles vaccination is much lower, at 42%. The rate varies widely across countries: in the UK, 60% of participants have heard of the vaccine, while in the Netherlands, this number is just 10%.





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Uptake was even lower than awareness. On average, only 8% of participants have received the shingles vaccine.

The highest uptake rate is in the UK, where 23% have received it. In the UK, the NHS funds vaccination for those aged 70-79: in this age group, 58% of participants have received the vaccine. The UK has the strongest shingles vaccination programme of all the countries we surveyed. It's the only country that invites residents for vaccination when they are of eligible age, through phone calls, texts, emails or letters, depending on the patient's contact preference.<sup>56</sup> Uptake is second highest in Greece, which also has a strong programme.

However, the UK's uptake rate of 23% is still low. Shingles has been allowed to fall through the cracks, despite its impact on individuals and communities. All the countries we surveyed clearly struggle with vaccination awareness and uptake. High uptake of flu and COVID-19 vaccination shows that strong, publicised vaccination programmes work.

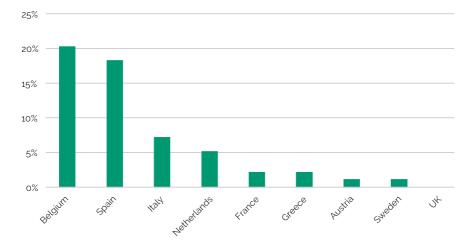
Combined with our participants general attitude to the importance of vaccination, this suggests that Europe's problem with vaccination uptake isn't primarily caused by hesitancy, but rather a lack of awareness. This most probably stems from poor public health communication and weak vaccination programmes.

## Assessing shingles awareness

- Over one in twenty of Europeans have never heard of shingles, and this figure is much higher in Belgium and Spain.
- Europeans generally have little knowledge of what causes shingles and the age groups who are most at risk.
- General knowledge about shingles is worse in countries with weaker vaccination programmes.
- Doctors don't inform patients of the risk shingles poses to their health.
- Participants who have been informed about shingles by their doctor, and those with better knowledge of the disease, are more likely to get vaccinated.

## How much do people know about shingles?

Not only is shingles vaccination awareness extremely low across all the countries in this study, but levels of understanding and awareness of the disease itself are concerningly poor.



#### Figure 3: Percentage that haven't heard of shingles by country

Across all the countries surveyed, 6% of participants have never heard of shingles. Lack of knowledge doesn't correlate to the strength of national vaccination programmes.

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## Low awareness of shingles

The percentage who haven't heard of shingles is highest in Belgium, at 20%. Belgium's vaccination programme is poorly funded, with a convoluted vaccination process that has led to low vaccination rates. This, in turn, has resulted in low knowledge about shingles.

But the figure is also very high in Spain, at 18% – this is a country with a relatively strong vaccination programme, and generally positive attitudes towards vaccination. Spain's poor knowledge likely stems from vast regional differences within its decentralised healthcare system. Participants from the southern region of Spain are more likely not to have heard of the disease – with southern regions like Andalusia and Murcia being among the least funded regions.<sup>57</sup> Italy also has a relatively high figure at 7%, while being in the minority of countries that fully fund vaccination, and the third highest uptake level.

### Higher awareness of shingles

Participants from Austria and Sweden have good knowledge of the disease, even though vaccination programmes are weak or non-existent. Only 1% of participants from Austria haven't heard of shingles. Austria's vaccination process is relatively simple to navigate, but lack of funding and communication about vaccination makes it weaker. Sweden doesn't have an official recommendation for shingles vaccination at the time of publication, but its participants have some of the best knowledge of shingles in this study. It also has a higher vaccination rate than over half of the countries included in this survey.

Sweden's public health education and health literacy is among the best in the world.<sup>58</sup> This high level of general health literacy means that its people are exceptionally healthy, with one of the highest life expectancies in the world and one of the lowest rates of infant mortality.<sup>59</sup> This makes it likely that people there simply make more informed decisions about vaccination and elect to pay for it themselves. In addition, Sweden's healthcare system and attitudes tend to focus on prevention, and there's a strong culutre of accessing vaccinations privately.

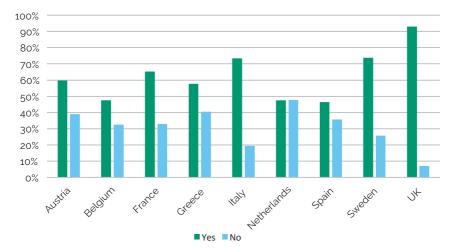
### Focus on prevention makes a difference

National health systems always focus on a mix of preventative and curative care, though spending in these areas varies greatly across countries. Countries with lower preventative care spending, including Austria and Belgium, tend to perform worse in this survey. Countries with higher preventative spending, like the UK, Sweden and Italy, perform far better. A culture of prevention translates into better vaccination uptake and better disease knowledge.<sup>60</sup> That being said, a broadly high uptake of flu and COVID-19 vaccination indicates that people aren't necessarily averse to individual instances of preventative care. Knowledge and a culture of prevention need to go hand in hand to encourage uptake.

## Do people know where shingles originates?

Awareness of the existence of shingles doesn't necessarily translate into an advanced understanding of the disease.

Awareness of the link between chickenpox and shingles varies greatly across countries.



#### Figure 4: Is there a link between shingles and chickenpox?

Countries with strong vaccination programmes show a good level of knowledge of the link between chickenpox and shingles. 93% of participants from the UK are aware of the link. Italy, with its fully funded, strong programme, also has a relatively high level of awareness.

But in Greece and Spain the strong uptake of vaccination, and specifically shingles vaccination, doesn't translate into good knowledge of the disease. Only 58% of Greek and 46% of Spanish participants know about the link. On the other hand, Sweden is second only to the UK in terms of this knowledge, with 74% of participants being aware.

### Weak vaccination programmes are linked to lower awareness

These exceptions aside, awareness is lowest in countries with weaker vaccination programmes. In France, based on recommendations from July 2023, individuals require a prescription before receiving the vaccine. The vaccine can then be administered by various healthcare professionals that aren't GPs, but the programme is generally a more complex, longer process than is found in stronger programmes like the UK's.<sup>61</sup> This puts France in the middle of the pack for strength of vaccination programme, similar to its participants' levels of knowledge.

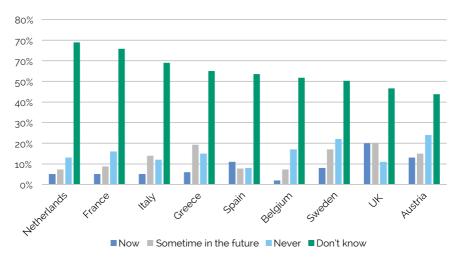
In Austria, where vaccination is relatively easy to arrange privately but not funded, knowledge is slightly worse, but the lowest level of knowledge is in the Netherlands and Belgium, where vaccination programmes are weak and poorly communicated, and there are lower levels of knowledge about the disease. In fact, the Netherlands is the only country where the number of participants who believe there's no link between shingles and chickenpox (47.76%) is higher (albeit marginally) than the number who believe there is a link (47.51%).

Poor knowledge of the link between these two illnesses is likely to affect vaccination uptake. If people are unaware that the virus may be lying dormant in their bodies, they're less aware of the risk of developing shingles, and may be less likely to seek vaccination.

In fact, this survey discovered that many don't understand the level of risk they face.

## Do people know when they're at risk?

We can get shingles at any age, but it's most likely to affect people aged 50 and over,<sup>62</sup> meaning that all our participants are currently at risk of developing it. Only 8% recognised this fact – the response options were 'now', 'sometime in the future', and 'never'.



#### Figure 5: When do you think you'll be at risk of developing shingles?

Awareness of the age groups at most risk is highest in the UK. Here, about 20% of participants say they think they're at risk now, and another 20% say sometime in the future.

But even in other countries with stronger programmes, like Greece, Italy and Spain, awareness of the age groups most at risk is extremely poor. More participants say they're at risk of developing shingles 'in the future' rather than 'now' in every country except Spain. And 15% of Greek participants say they'll never be at risk, although, at 19%, more say they'll be at risk in the future.

In fact, many participants say they think they'll 'never' be at risk, with the proportion far higher in countries with weaker vaccination programmes. 'Never' is the second-highest response in the Austria (24%), Sweden (22%), Belgium (17%), France (16%), and the Netherlands (13%). Shingles vaccination programmes are poorly funded, complex or weak in all these countries, except Sweden, which doesn't have one at all.

### Most participants don't know their risk of shingles.

Even in the countries with the strongest programmes, the majority response is 'don't know', with 55% of all participants selecting this.

This response was highest in the Netherlands, at 70%, where the vaccination programme is inadequate. Italy, Greece, and Spain all

had high percentages as well, despite having strong vaccination programmes and positive attitudes towards vaccination.

Participants from countries like Austria and Sweden are less likely to say they don't know, but only because they're more likely to think they'll never be at risk. Austria has the lowest number selecting 'don't know', at 54%, but the highest number selecting 'never'. Similarly, Belgium has fewer 'don't know' responses, but in this case, 'NA – I have never heard of the shingles virus' accounts 20% of all responses.

It's clear that every country has a problem with knowledge of which age groups are most at risk. This lack of knowledge means a high risk of future vaccination complacency. If people aren't aware they're at risk, why would they vaccinate, particularly in places where the process is difficult, expensive, and complex? Similarly, if people aren't aware of the severity of the disease, they may also be complacent about vaccination.

## Do people know how severe shingles can be?

In most cases, shingles is considered a disease with moderately severe symptoms. Depending on complications, it can also be considered severe, and in rare cases it can be life threatening.<sup>63</sup> In most of the countries in our survey, less than 10% of participants think shingles is a disease with minor consequences.

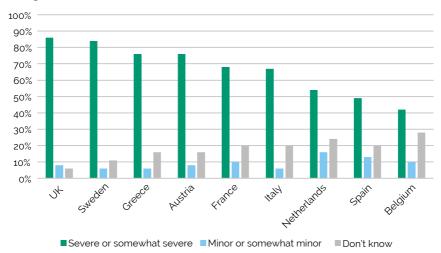


Figure 6: How severe are the symptoms and consequences of shingles?

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There's a link between the strength of a country's vaccination programmes and participant knowledge that shingles is a 'severe or somewhat severe' disease. Over 80% of British participants correctly recognise the severity of the disease, as do 76% of all Greeks. In the Netherlands and Belgium, they're far less likely to believe the disease is more severe: over 20% in both countries responded 'don't know'.

On the other hand, participants from Austria and Sweden are more likely to recognise the severity of shingles despite the weakness (or non-existence) of their vaccination programmes. Sweden was the second least likely to answer 'don't know' behind the UK, and the least likely to believe shingles is a minor disease. Greece, despite participants generally having a good level of knowledge about the severity of shingles, had a higher number of 'don't know' responses than Sweden.

It's concerning that 18% of all participants, and over 10% of participants from every country except the UK, didn't know the severity of the disease.

There appears to be a clear pattern. Participants from UK and Sweden are consistently the most knowledgeable and those from the Netherlands and Belgium are generally the least. Greek participants lack knowledge despite the country's strong vaccination programme and relatively high uptake, while Austria, France and Italy are in the middle.

The high uptake but low levels of knowledge in Greece may be related to the fact that public trust in GPs is high.<sup>64</sup> It's possible that although people have lower levels of knowledge of the disease, trust in their doctors encourages vaccination uptake nevertheless.

## Are doctors telling people about shingles?

Doctors generally play a vital role in disease awareness and vaccination uptake. During the COVID-19 pandemic, they were on the frontline of public education about the virus and its prevention.<sup>65</sup> Healthcare professionals worked hard to dispel myths and vaccine hesitancy and have done so in other situations too, including attempts to ease hesitancy about the MMR vaccination due to the myth that it causes autism.<sup>66</sup>

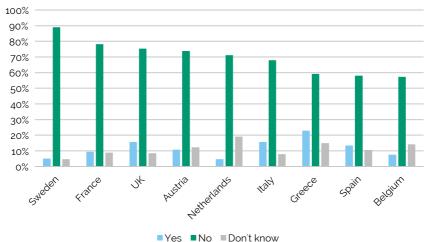


Figure 7: Has your doctor told you about the risk of shingles?

But when it comes to shingles, it seems that some doctors aren't informing patients in the same way. There's a slight link between stronger vaccination programmes, and the level of information from doctors. Greece, the UK, and Italy are the three countries in this study with the highest level of communication from doctors about the risks associated with shingles. They're also the three with the highest uptake, and the only three that fully fund vaccination. But the highest rates of communication aren't necessarily high.

Communication from doctors is generally poor. 70% of all our participants haven't been informed of shingles risks by their doctors. In countries with complex vaccination programmes, lower funding, or no vaccination recommendations at all, participants are even less likely to say their doctor had informed them. Only 5% of participants from Sweden and the Netherlands said their doctor had informed them. Everyone surveyed is over 50, and therefore currently at risk for more severe shingles infections. Communication from doctors is an important factor in not only encouraging vaccination uptake, but also improving knowledge and awareness of the disease.

## How do doctors affect knowledge levels?

Participants who have been informed by their doctor about the risk of shingles are less likely to think they would never be at risk of developing the disease. 24% of Austrians think they'll never be at risk: only 11% say they've been informed of the risk of shingles by their doctor. On the other hand, only 15% of Greek participants think they'll never be at risk, with 23% having been informed of the risk. The same can be seen in Italy and the UK: only 12% and 11% respectively think they'll never be at risk, while 16% had been informed in both countries. However, there was little correlation between being informed by a doctor and knowing the age groups most at risk. Most participants still don't know this, regardless of whether their doctor had informed them or not.

In terms of symptom awareness, those who were informed by a doctor are more likely to recognise shingles as a severe disease. In the Netherlands, 16% thought shingles was a 'minor or somewhat minor' disease, and 24% weren't sure. Only 5% of these participants had been informed of the risk of shingles by their doctor.

Knowledge of the origins of shingles is generally better in countries with better communication from doctors. In the UK and Italy, 16% of participants said their doctor had informed them about shingles. 93% and 73% respectively knew about the link between shingles and chickenpox. But in the Netherlands, where people are less likely to have been informed by their doctor, a slight majority believe chickenpox and shingles aren't linked. Again, the exception to this pattern is Sweden. Despite only 5% of Swedish participants being informed of the risk by their doctor, knowledge of the disease's severity and origins is consistently among the highest.

As previously mentioned, doctors play an important role in vaccination uptake, as evident during the COVID-19 pandemic. When it comes to shingles, it's clear that the role of healthcare professionals is just as vital.

## How do doctors affect vaccination uptake?

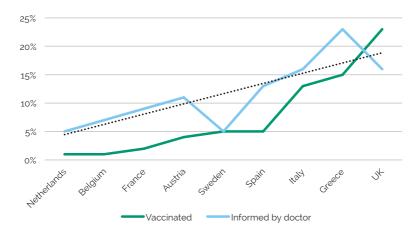


Figure 8: Correlation between uptake and HCP communication, by country

There's a strong positive correlation between doctors informing their patients of the risks and the level of vaccination uptake. In Austria, the vaccination rates are higher than in France, although France offers free vaccination through insurance reimbursement and Austria has no funding. Austrians are also more likely to have been informed about the risk by their doctor. Belgium and the Netherlands have both the lowest levels of vaccination, and some of the lowest levels of participants having being informed by their doctors.

There are two outliers here: while only 5% of Swedish participants have been informed by their doctors, their vaccination rate is far higher than countries like the Netherlands and Belgium. This is likely due to Sweden's high levels of healthcare education.

The second outlier is the UK, the only country where the vaccination rate is higher than the rate of people being informed by their doctors. This is also surprising considering that the UK only offered vaccination for people aged 70-79 at the time of our survey, while some countries have a larger eligible age bracket. The high vaccination rate could be due to the UK's 'vaccination birthday cards' which are sent out to those who become eligible for vaccination.<sup>67</sup> On top of being informed by doctors, other processes within the healthcare system encourage uptake.

## How does knowledge affect vaccination uptake?

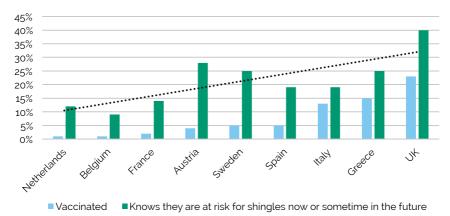


Figure 9: Correlation between knowledge and uptake, by country

There's a very strong positive correlation between vaccination uptake and knowledge of when one would be at risk for shingles.

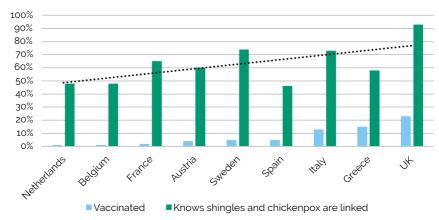


Figure 10: Correlation between knowledge of the link between shingles and chickenpox, and uptake, by country

There's also a relatively strong positive correlation between knowing chickenpox and shingles are linked and getting vaccinated.

This indicates that people who have a better understanding of the disease, aside from the fact that it's somewhat serious, are also more likely to vaccinate.

These two correlations suggest that as knowledge of shingles increases, so does vaccination. Increasing awareness of the disease is an important way to increase vaccination uptake and reduce the burden of shingles.

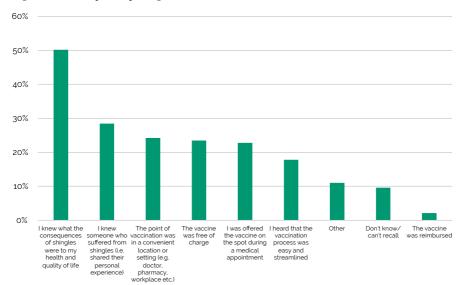
Of course, correlation doesn't always equal causation. To ensure a better understanding of what motivates people to get vaccinated, we asked participants to provide reasons for having received the vaccination.

## Barriers and opportunities in shingles vaccination

- Individual knowledge was the biggest motivator for those who have already been vaccinated.
- Stronger vaccination programmes offer vaccination on the spot during medical appointments.
- Cost and a lack of knowledge are the main barriers to uptake.
- Only 9% of participants are hesitant about the shingles vaccine.

## What encouraged participants to get vaccinated?

We asked participants who have been vaccinated to select one or more reasons why they did so from a fixed list. There were some clear patterns.



#### Figure 11: Why did you get vaccinated?

Note: "Vaccination process" refers to the entire process, including: deciding to get vaccinated; getting an appointment or walking into a pharmacy/doctor's office without an appointment; whether you can get the vaccination during that appointment or whether you need another.

Individual knowledge was a key response across the board. Half of all vaccinated participants cite knowledge of the consequences as a reason, while 28% knew someone who has had shingles. Ease of vaccination was another big motivator: many participants cite a convenient vaccination point, an easy vaccination process or being offered the vaccine on the spot during a medical appointment.

Cost was also a factor: just over 20% stating that they received the vaccine because it was free, and 2% said because the cost was reimbursed. However, it should be remembered that this isn't an option for all. The vaccine is only completely free at the point of vaccination in the UK, Greece and Italy. It's only funded for some groups in Spain and the Netherlands, in France only a partial rebate is available, and in Austria, Belgium and Sweden vaccination isn't funded at all.

## How does the strength of vaccination programmes affect participants' stated reasons for uptake?

Looking more closely at the difference in vaccination programmes, we can again see some patterns in stated reasons for uptake emerge.

In the UK, Greece and Italy, where vaccination is funded, participants were more likely to say they received it because it was free. More than half of all participants from the UK selected this reason, with over 40% also citing 'I was offered it on the spot during a medical appointment'. Knowing the potential health consequences of shingles and knowing someone who has had the illness was also cited in all three countries. Interestingly, these were the only countries where participants choose every possible answer.

In countries with semi-strong programmes, like Spain and France, a narrower range of reasons were cited. Spanish participants mainly selected price and convenience: 35% selected free vaccination, with 53% citing either a convenient point of vaccination, an easy process, or being offered it on the spot during an appointment. Cost was also a motivator in France. 29% of participants said they did so because the cost was reimbursed. Unlike in Spain, however, knowledge was another driving factor. Nearly 30% said they were vaccinated because they knew the consequences shingles posed to their health, and nearly 30% because they knew someone who has had the disease.

In the countries with the weakest (or non-existent) vaccination programmes – Belgium, the Netherlands, Austria and Sweden – far fewer participants cited an easy process, being offered vaccination on spot, or costs. Individual knowledge and first-hand experience are the biggest drivers; participants said they were vaccinated because they were aware of the consequences for their health or they knew someone who has had from the disease.

Uptake is certainly affected by the strength of vaccination programmes. In countries with stronger, well-funded programmes, participants were influenced by free vaccination, being offered it on the spot, and having a good understanding of the consequences, with many options cited. In places with weak, under-funded programmes, participants were almost solely motivated by individual knowledge and personal experience.

Individual experience is more limited and less reliable, which is evident when looking at the difference in uptake between countries with weaker and stronger programmes. And the influence of this experience is limited, with a higher potential for misinformation. But the strength of vaccination programmes isn't the only thing that affect uptake.

## What else affects the reasons participants gave?

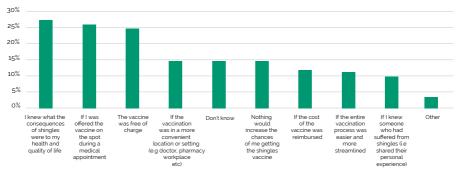
Participants who displayed an average level of knowledge about shingles showed some variation in their stated reasons for vaccination. While knowledge of the consequences was a motivator, participants in Spain, Austria, Greece and France were more likely to cite the vaccination process as another reason. These participants were also more likely to choose a combination of reimbursement, free vaccination, an easy process, and being offered the vaccine on the spot.

Participants' vaccination decisions are also tied to whether or not their doctor has discussed shingles with them. In countries with better-funded programmes – like the UK, Spain, Greece and Italy – participants were more likely to say they'd been offered vaccination on the spot. More participants from countries that fund vaccination also say that their doctors have informed them of the risks and are more likely to offer vaccination, suggesting a positive culture towards shingles vaccination.

This further demonstrates the importance of the role of healthcare professionals in encouraging uptake.

## What would encourage people to get vaccinated?

We asked participants who hadn't received the vaccine but who had heard of shingles what might encourage them to get vaccinated.



## Figure 12: What would increase your likelihood of vaccination in the future?

There were no easily discernible patterns in what might drive one to get vaccinated, with responses varying greatly from country to country.

## Understanding the consequences

Yet there are some common themes. Most said that understanding the consequences of shingles was the most important factor in deciding whether to get vaccinated. This answer was less common in countries where participants have high levels of knowledge, such as Sweden and the UK, but was still the most common answer overall. This was also the highest response in Spain, where 40% indicated that knowing more about shingles would encourage uptake.

Spain had the second highest percentage of participants who had never heard of shingles, and comparatively poor knowledge of the age groups at risk as well as the severity of symptoms. Other countries with poor or average levels of knowledge – Belgium, France, Greece and the Netherlands – indicated that a better understanding of the disease would encourage uptake. These results further highlight the importance of disease education.

### Being offered vaccination on the spot

The second most popular answer cited was being offered vaccination on the spot during a medical appointment.

## Personal experience counts too

Participants from countries with lower levels of knowledge are also more likely to say they would get vaccinated if they knew someone who has had the disease. Although this was a less common answer, previous research also shows trust in healthcare increases when people see themselves and their own personal experiences reflected in public health campaigns or health education materials. A recent study found Black Americans were more likely to receive the COVID-19 vaccine when they saw people who looked like them receive the vaccine.<sup>68</sup> Research around representation in healthcare and its impact always draws clear conclusions: representation matters. Sharing an individual experience and knowing someone who has had shingles is a common response when we ask unvaccinated participants what might persuade them, but it was also cited as a reason by those who have already been vaccinated.

### Cost is up there

Cost was another driving factor for participants from every country, either in the form of free vaccination or reimbursement. This was higher in countries that don't fund the vaccine. In Sweden, 44% said they would be more likely to get vaccinated if it were free. Even in countries where vaccination is fully funded for specific age groups, this was a common answer. One in five vaccine-eligible respondents from the UK and Italy said they would be more likely to receive the vaccine if it was free. The same can be seen for 15% of eligible Greek respondents, suggesting a need for better education on what's available through national healthcare systems.

### Easy access is less of a motivator for now

Ease of vaccination seems to be less of a factor. Only 9% and 7% of participants chose 'a more convenient setting' and 'an easier, more streamlined vaccination process' respectively. Even participants from countries with complex vaccination processes, like Belgium, chose these options less.

In fact, only participants from countries with relatively strong vaccination programmes tend to choose these options. In the UK, they comprised 21% of the total responses to this question, while in Italy they comprised 29%. But in Belgium, which has one of the more complex processes, they only accounted for 11% of total responses. Cost and knowledge were cited far more.

This suggests knowledge and cost are the most basic drivers, and what weaker programmes should focus on for improvement of uptake. Once individual countries have strengthened their programmes, offer free vaccinations, and ensure more knowledge of the disease among individuals, their public health services can turn to improving programmes with more convenient points of access and more streamlined processes.

9% of all participants say they don't know what might increase their likelihood of vaccination. Even in Greece, the country with the highest level of participants to be informed by their doctors, 11% gave this answer. This suggests a need to examine different avenues in encouraging vaccination uptake, such as the involvement of community organisations; there's evidence elsewhere that community engagement and involving trusted community leaders in vaccination campaigns does improve vaccination uptake and acceptance.<sup>69</sup>

Overall, 85% of the participants who have heard of shingles but haven't been vaccinated say they would get vaccinated if there were some changes in vaccination programmes. Hesitancy isn't the main issue. People are willing to vaccinate providing we remove the barriers to vaccination. Addressing these barriers, and improving vaccination policies and programmes, are now key to encouraging higher uptake.

## **Our recommendations**

#### Investing in systems designed for prevention:

- EU member states and the UK should have a clear target to vaccinate 75% of the eligible population against shingles.
- Every country should officially recommend the shingles vaccine for older and immunocompromised individuals.
- Vaccination should be fully funded.
- The vaccination process should be easy and streamlined, possibly by:
  - vaccination piggybacking
  - o offering the vaccine on the spot in medical appointments
  - ° removing barriers like the requirement for a prescription

#### Actions to inspire and engage:

- Every country should have comprehensive communication campaigns to encourage uptake, which could include:
  - call-and-recall programmes for those of eligible age
  - o shingles birthday cards
  - representative campaigns that leverage personal stories
- Healthcare providers should actively inform patients about the risk of shingles and encourage vaccination uptake.
  - Programmes or initiatives that encourage healthcare workers to proactively converse with their patients about shingles and offer the vaccine are vital.
- Governments and healthcare professionals should also work with trusted community organisations to further encourage the dissemination of information and uptake of vaccination.
  - This not only addresses vaccine hesitancy and vaccine inequity, but also takes some pressure off overworked, under-resourced healthcare systems.

#### Actions to democratise access to prevention:

- Vaccination should be made more widely available in various healthcare settings in addition to GP surgeries, including pharmacies, workplaces and other community areas.
- Resources and access must be equitably distributed across regions within countries, with each country ensuring an adequate and equitable allocation of funds based on regional needs.

### Actions to support the effective use of technology:

- Governments and healthcare systems should ensure that reporting and data collection is more comprehensive and is required at regional, country and European levels.
  - This data tracking should include rates of infection, vaccinations and regional hotspots, as well as who is fully vaccinated and who still needs to be protected.
- To ensure consistency, healthcare systems should implement automated reminder services for healthcare professionals that remind them to recommend and encourage vaccination when eligible individuals have appointments for other issues.

## First priority for each country

All of our recommendations should be implemented in every country, but there is a key focus area for each country:

**Austria** should encourage healthcare professionals to inform patients about shingles and encourage vaccination, with the support of reminder systems.

• Why? Austrians are the most likely to believe they'd never be at risk for shingles, and communication levels are low. Austrian participants also indicated that they would be more likely to vaccinate if it were proactively offered.

**Belgium** should implement comprehensive information campaigns both via and separate from GPs and other healthcare professionals, to build public knowledge and encourage vaccination uptake.

• Why? Belgium's largest barrier to uptake is arguably the fact that 20% of participants have never heard of shingles. Knowing the consequences shingles has on one's health is also the most common answer for what would encourage them to vaccinate.

**France** should encourage healthcare professionals to inform patients about shingles and encourage vaccination, with the support of reminder systems.

• Why? Two thirds of French respondents aren't sure when they'd be at risk for shingles, and less than 10% had been informed of the risk by their doctors. Nearly 30% of unvaccinated participants indicated they were more likely to vaccinate if they had a better understanding of the consequences of the disease.

**Greece** should involve trusted community organisations in campaigns to improve knowledge, and therefore uptake.

• Why? Greece has one of the best shingles vaccination programmes in Europe and has good uptake compared to the other countries in this study, with good levels of communication from doctors. Despite this, Greek participants' knowledge of shingles is still lower than those from many other countries.

**Italy** should improve vaccination accessibility by offering it more widely in pharmacies and encouraging doctors to offer it on the spot to eligible patients.

• Why? Italy has one of the strongest vaccination programmes and high uptake compared to the other countries in this study, but our survey found one clear barrier in the vaccination process. Italians said they'd be more likely to vaccinate if they were offered the vaccine on the spot in a medical appointment or if the vaccine was available in a more convenient setting.

**The Netherlands** should implement extensive and wide-reaching communication campaigns about shingles and vaccination, and healthcare professionals should be allowed to communicate with patients about the risks of shingles and the importance of vaccination.

• Why? Knowledge on all fronts is a major challenge in the Netherlands. Only 12% of Dutch participants knew there was a vaccine for shingles, compared to the average answer of 42%. It regularly ranked among the lowest in survey questions that assessed knowledge. Additionally, the overwhelming response to what would encourage vaccination was a better understanding of the consequences shingles would have on one's health. **Spain** should administer more equitable healthcare funding to poorer areas to facilitate vaccination efforts.

• Why? Spain's challenge is different to other countries: while there are some issues around knowledge of both the vaccine and the disease, these results varied greatly across regions. Spain's decentralised healthcare system has left some areas underfunded and struggling, particularly in the south. The most important step Spain can take is to promote equity between regions, in terms of financing and vaccine provision.

**Sweden** should add the shingles vaccination to their vaccination programme and fund it fully.

• Why? Throughout this report, it's been evident that Sweden is an outlier. It's the only country with no recommendation or vaccination programme, yet its participants have some of the best knowledge of shingles, and the fourth highest uptake of all countries included in this study. Nearly half of all unvaccinated Swedish participants indicated that they would get vaccinated if it were free.

**The UK** should offer the vaccination for free in pharmacies and encourage more doctors to offer vaccination on the spot in medical appointments.

• Why? Like Italy and Greece, the UK has a strong vaccination programme. In this survey, UK participants ranked well in knowledge and uptake. A recent change in the UK's vaccination recommendations also sees the shingles vaccine being more widely accessible to different age groups. With this strong foundation, the UK can now focus on more nuanced aspects of the vaccination process. Participants indicated that they'd be more likely to get vaccinated if they were offered it on the spot and if it were available in more convenient locations.

## Conclusion

Vaccinating against shingles is an essential part of healthy ageing for Europe. Shingles cases are common, and the illness can have a significant impact on quality of life, particularly for older people. Common complications like PHN are more likely for older people, costing healthcare systems and economies millions every year. Vaccination helps protect older people from the disease and its complications.

Europe is ageing, and with that comes an increased risk of shingles. Shingles is a preventable disease, but vaccination rates are low across the continent. The vast majority of people are open to getting the shingles vaccine, but there are a number of barriers to uptake, including lack of knowledge about the disease, cost, and difficulty accessing the vaccine. Fully funded, easily accessible vaccinations with clear targets are essential. Governments and healthcare providers also need to inspire and engage with the public, improve access, and use technology effectively to support vaccination efforts.

The vast majority of people who participated in our survey are open to the idea of vaccinating for shingles. They understand and agree with the importance of vaccination, but there are challenges associated with increasing uptake.

Even though our participants are generally aware of the existence of shingles, deeper knowledge of the disease is lacking. Participants are unsure about its severity, at what age people are most vulnerable, and where the disease originates. We know that healthcare professionals play a key role in imparting knowledge and encouraging vaccination for diseases, but this hasn't been the case for shingles. Most participants haven't been informed by their doctor about the risk shingles poses to their health.

For those who have been vaccinated, knowledge of the health consequences of shingles was the biggest motivator behind their decision. In countries with strong vaccination programmes, free vaccination and an easy process also encouraged uptake. Healthcare professionals offering vaccination on the spot and informing their patients of the risk of shingles also increases uptake.

But there are also barriers. Vaccination programmes are currently not strong enough in many countries. Most don't fund vaccination, and

it's expensive to get privately. A lack of knowledge surrounding the subsidies available in certain countries also hampers uptake. There can be difficulty accessing vaccination in a convenient location, and overly complex vaccination processes. Not knowing the consequences of shingles also presents a barrier to uptake.

Our recommendations have been created to explicitly address these barriers. Fully funded, easily accessible vaccination programmes with clear targets for coverage are vital if we are to focus on preventing shingles, not just treating cases. We need healthcare professionals to get involved if we are to inspire and engage with the public to encourage uptake. We also need comprehensive communication campaigns and collaborations with trusted community organisations.

We can improve access through a more equitable distribution of resources across regions, and by making vaccination available in a variety of easily accessible locations, not just doctors' offices. Finally, we must use technology effectively to support vaccination efforts. We must implement thorough data collection and reporting to understand rates of infection and vaccination better. We can also create automated reminder systems to support healthcare professionals in their efforts to encourage vaccination.

Vaccination is a proven way to ensure healthy ageing, but it only works if governments and health systems prioritise and fund it.

## Appendices

| Appendix 1: Updated country | recommendations |
|-----------------------------|-----------------|
|-----------------------------|-----------------|

| Country     | Recommended age as of April 2024   | State<br>funding |
|-------------|--|------------------|
| Austria     | 50+  | No               |
| Belgium     | 16+ if immunocompromised<br>60+  | Partial          |
| France      | 18+ if immunocompromised<br>65+  | Yes              |
| Greece      | 18+ if immunocompromised<br>60+  | Yes              |
| Italy       | 18+ if immunocompromised<br>65+<br>[some differentiation across regions] | Yes              |
| Netherlands | 18+ if immunocompromised<br>60+  | Partial          |
| Spain       | 18+ if immunocompromised<br>65+<br>[some differentiation across regions] | Yes              |
| Sweden      | No recommendation  |                  |
| UK          | 50+ if immunocompromised<br>65<br>70-79                                  | Yes              |

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ILC is the UK's leading authority on the impact of longevity on society. We combine evidence, solutions and networks to make change happen.



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