Data, bots and drones

Can technology help increase uptake of adult immunisation?
Background

In June 2018, ILC-UK published *The Future of Adult Immunisation*, a think-piece exploring the potential of technology to influence the delivery and uptake of vaccination. Designed to be a prompt to further debate, the paper looked at different strands of technology that might have a role to play in increasing vaccination coverage, broadly divided as follows:

- Better use of data
- The internet
- The internet of things
- Gamification
- The sharing economy
- Artificial intelligence (AI) and robots
- Blockchain
- Materials science

The paper was a catalyst for debate at a futures workshop held in Brussels later that month, at which we brought together experts in technology, innovation, and adult vaccination. During the workshop, this expert group was asked to consider:

- What are the barriers to uptake of adult vaccination?
- How might technology help improve the uptake of adult vaccination?
- What might impede the use of technology here?
- What should policymakers do to ensure that we maximise the potential of new technology?

This final report sets out the ideas that emerged at that meeting and makes recommendations for policy change. We address these questions according to the different aspects of new and emerging technology outlined above: in practice, of course, there is considerable overlap between technologies - the overlap of AI and big data being just one obvious example. Some of the policy directions that emerged from the meetings are specific to particular uses of technology. Others – such as rigorously evaluating what works or ensuring patients are central to solutions – apply equally across the board.
Inevitably, given the involvement of such a large group of experts, we cannot claim to represent the views of all participants. This report therefore represents the views of ILC, rather than of all the workshop participants.

Speakers at the event in June included:
Lana Crnjac, Interim CEO, European Liver Patients’ Association
Dave Eaton, Policy and Public Affairs Manager, ILC-UK
Elena Gentile MEP, European Parliament
Michael Greenberg, MD, MPH, Vice President and Head, Global Medical Strategy, Sanofi Pasteur
Julie Girling MEP, European Parliament
Daphne Holt, Chair, Coalition for Life-Course Immunisation
Prof Pier Luigi Lopalco, Department of Translational Research and New Technologies in Medicine and Surgery, University of Pisa, Italy
Peggy Maguire, Director General, European Institute of Women’s Health
Dr Isabel De La Mata Barranco, Principal Adviser for Health and Crisis Management, DG SANTE
David Salisbury, Centre on Global Health Security, Chatham House, London
David Sinclair, Director, ILC-UK
Marius Tudor, Project Manager, EPHA
Philip Weis, Chairman, ZN Consulting
Bogdan Wenta MEP, European Parliament
Dr Wendy Yared, Director, Association of European Cancer Leagues

Unless otherwise specified, the quoted comments in this report are from the workshop.

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Summary

Through the use of big data, the sharing economy and AI amongst others, technology could play a major role in overcoming some of the barriers to the uptake of adult vaccinations.

While growing anti-vaccination sentiments have been impacting on immunisation uptake across the globe, a “fightback” has begun with pro-science doctors and healthcare organisations developing a more savvy online presence and better content to respond to the anti-vaccination movement.

This report highlights some of the ways in which technology is already being developed to break down the barriers to vaccination:

- The UK leads the world in using weekly data to help support uptake of influenza vaccination by older people.
- The US-based healthcare transport company Circulation, has begun to leverage ride-sharing services such as Uber and Lyft to take patients to healthcare appointments.
- Mark Kendall from the University of Queensland is developing a postage- stamp sized nanopatch with thousands upon thousands of tiny spikes on its surface, which could be used as an alternative to the needle for delivering vaccination.
- In India, a medical student has devised a digital necklace, which stores a wearer’s medical history, including vaccination records.

The report presents findings from a futures workshop held in Brussels in 2018. As part of the event, NGOs, expert policymakers and healthcare professionals suggested their own ideas for using technology to support uptake of adult immunisation. Ideas included:

- Influencers on Instagram could address adult immunisation and encourage younger generations to talk to their grandparents.
• Wearable technology could measure our vital signs and signal when something isn’t normal. Personalised vaccination recommendations could be incorporated into smart watches.
• A virtual lifelong personal health assistant could give us advice on health behaviour and remind us of the need for regular screenings.
• Location based alerts could prompt people to get vaccinated (e.g. when at risk groups are near somewhere they can receive a vaccination).
• Immersive virtual reality could help people realise the impact of serious diseases.
• Siri, Alexa and Google Home could help us book our vaccination appointment.
• A pharmacy app could help with record keeping and vaccine booking.
• “Bots” could deliver information and have conversations with people about their concerns.
• An app could allow patients to ask questions anonymously of doctors or other specialists and get an instant reply.
• Bar-coded information on vaccinations to track and trace who has been vaccinated and linked into medical records.

Among a set of recommendations in the report, ILC calls on European policymakers to:

• Develop a specific funding programme on “what works” to ensure that policy and financial investment in technology delivers its potential;
• Legislate to ensure that products and services are accessible and usable for all ages and abilities;
• Recognise the challenges of demographic change and ageing populations and ensure policy supports vaccination as important across our lives;
• Develop an EU wide programme of action to encourage uptake of adult as well as child immunisation.
## Contents

Introduction ................................................................. 7
Why does adult immunisation matter? ...................... 11
Using better data ......................................................... 13
The internet ................................................................. 21
The internet of things .................................................. 28
Gamification ............................................................... 31
The sharing economy .................................................... 33
AI and robots ............................................................. 35
Blockchain ................................................................. 37
Materials science ......................................................... 39
Recommendations ....................................................... 40
Introduction

It has been estimated that vaccination saves almost 6 million lives worldwide every year.\(^1\) Vaccines are also cost-effective, calculated to save tens of billions of dollars annually.\(^2\) Yet vaccine-preventable diseases – which affect the youngest and the oldest disproportionately – continue to affect the health of many people around the world, including in Europe.

There is a clear case for adult immunisation. In England, the influenza vaccine averts between 180,000 and 626,000 cases of influenza a year and helps save between 5,678 and 8,800 lives.\(^3\) Vaccinations both benefit individuals and prevent the spread of epidemics. At a time of increasing concern about antimicrobial resistance, vaccination has an important part to play.

Despite the clear case for widespread vaccination coverage, uptake is not as high as it might be. In 2017, Jean-Claude Juncker, President of the European Commission, called in his State of the Union address for action to increase coverage and ensure that everyone in the EU has access to vaccines. Whilst there is rightly concern about the falling childhood vaccination uptake levels, it is also worrying that so many older people do not benefit from the vaccinations which they are eligible for and would benefit from.

This report looks at the role technology might play in increasing vaccination coverage, drawing on a futures workshop in Brussels hosted by ILC-UK on 26 June 2018, which was attended by experts from across Europe. The workshop took place against a background of recent leadership on vaccination from European policymakers: in April 2018, the European Commission published 20 recommendations on fighting vaccine-preventable diseases.\(^4\) In the same month, the Commission also issued a Communication calling for more and better use of digital technology in managing health.\(^5\) The recommendations for strengthened cooperation against vaccine-preventable diseases were endorsed by the Council of the European Union in December 2018.\(^6\)

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2 Ehreth J. ibid
3 An Economic Analysis of Flu Vaccination (2018) International Longevity Centre - UK
In this report, we consider the importance of adult vaccination and review the barriers to uptake. Chief among these are that: people do not know they are eligible for vaccination; they decide not to be vaccinated; and they lack access to vaccination.

Technology offers a way to communicate the broad messages of the importance of vaccination and herd immunity. It also has the potential to target particular groups and individuals who are doubtful about the need to be vaccinated – or who have decided not to be vaccinated – much more specifically. As well as informing, digital technology offers ways to nudge and remind – and also, to change perceptions. In its ability to target messages and responses, it offers the possibility of more efficient use of resources.

There are, however, some barriers to the use of technology in increasing the uptake of vaccination, and these were discussed at the workshop. The main concern was seen to be public trust in new technology (embracing questions of privacy, data sharing, ethics and how to achieve population consent). Digital exclusion was also seen to be a potential problem when trying to engage older adults through technology. There were also concerns about affordability: would technology be deployed primarily by private healthcare systems or in other ways that increased social inequality?

Brainstorming at the workshop threw up a range of ideas for how technology could be used to increase vaccination uptake, which are included as prompts for discussion.

Policy directions were highlighted by the experts at the session. These focused mainly on two areas: the need to gather and use data better and the need to use technology to counter misinformation and fake news about vaccination.

At the end of the report, we make a number of policy recommendations. We see this report as a starting point for action and would welcome views on how to take this agenda forward.
European policy initiatives

Digital Health and Care

European Commission:

1. Secure access and exchange of health data

- Ambition: Citizens securely access their health data and health providers (doctors, pharmacies) can exchange them across the EU.
- Actions:
  - eHealth Digital Service Infrastructure will deliver initial cross-border services (patient summaries and ePrescriptions) and cooperation between participating countries will be strengthened.
  - Proposals to extend scope of eHealth cross-border services to additional cases, e.g. full electronic health records.
  - Recommended exchange format for interoperability of existing electronic health records in Europe.

2. Health data pooled for research and personalised medicine

- Ambition: Shared health resources, data, infrastructure, expertise allowing targeted and faster research, diagnosis and treatment.
- Actions:
  - Voluntary collaboration mechanisms for health research and clinical practice (starting with “one million genomes by 2022” target).
  - Specifications for secure access and exchange of health data.
  - Pilot actions on rare diseases, infectious diseases and impact data.

3. Digital tools and data for citizen empowerment and person-centred healthcare

- Ambition: Citizens can monitor their health, adapt their lifestyle and interact with their doctors and carers (receiving and providing feedback).
- Actions:
  - Facilitate uptake of innovative digital-based solutions for health, notably by healthcare authorities and providers, with exchange of practice and technical assistance.
  - Mobilise more efficiently public funding for innovative digital-based solutions for health, including EU funding.

The EU Commission’s Communication on the digital transformation of health and care, published in April 2018, argued that high-performance computing, data analytics and artificial intelligence can help improve the design and testing of healthcare products and provide faster diagnosis and better treatments. The paper looked at ways of collecting data, questions of cybersecurity and citizens’ access, and using data to promote research, disease prevention, and personalised health and care.

In April 2018, the Commission also published 20 recommendations to strengthen cooperation over vaccinations across Europe, which were duly endorsed by the Council of the EU in December 2018.

The recommendations where tech provides solutions include:

- Establish a European Vaccination Information Sharing (EVIS) system, which would help to coordinate vaccination schedules across Europe;
- Strengthen transparency in vaccination monitoring systems;

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• Design guidance on better collection and use of data for monitoring vaccination coverage;
• Look at options for a common vaccination card that can be shared electronically across borders;
• Establish a European vaccination information portal by 2019 to provide online objective, transparent and updated evidence on the benefits and safety of vaccines;
• Counter online misinformation;
• Develop online information tools to counter vaccine hesitancy;
• Develop an EU data warehouse with information on vaccine stocks and facilitate exchange of information on available supplies and shortages of essential vaccines.

These ambitions are underpinned by a €5.8m investment in a Joint Action on Vaccination\(^9\) involving 23 countries, which held its first meeting in Paris on 4 September 2018. This initiative aims to foster long-lasting cooperation across Europe by tackling vaccine hesitancy, ensuring sustainable vaccination policies across member states, and supporting Europe’s role in contributing to global health.

\(^9\)https://ec.europa.eu/health/vaccination/overview_en
Why does adult immunisation matter?

Vaccination offers cost-effective protection against a host of diseases throughout the life course. Despite this, it is commonly thought of as an intervention designed for children rather than adults – and, as a result, it remains an underused public health strategy for the promotion of healthy ageing. As the authors of a recent paper published in *European Geriatric Medicine* observe, “Without specific vaccination programmes for the adult population aged > 50 years, infectious diseases will continue to be a cause of substantial morbidity and mortality in late adulthood.”

Preventable illness can have an impact on caring responsibilities and on healthy ageing generally and places a severe burden on the health service. As well as the direct costs of hospitalisation, preventable illnesses lead to productivity losses as a result of poor health and premature death.

- The highest prevalence of influenza complications occurs among older adults, especially those with chronic medical conditions or immunological disorders, resulting in increased mortality.
- You are 50 times more likely to die from flu if you have chronic liver disease or if you are immunosuppressed. If you are in any medical risk group, you are 11 times more likely to die from flu than if you are not.
- In one study, older people given an influenza vaccine had approximately 20% less chance of suffering cardiovascular and cerebrovascular disease and 50% lower risk of mortality from all causes compared to their unvaccinated counterparts.
- In the EU, between 40,000 and 220,000 deaths per year

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might be attributed to influenza infection, depending on the pathogenicity of the circulating viral strain.\textsuperscript{14}

- In France, during the 2014–15 influenza season, there were about 2.9 million medical consultations, 30,000 emergency room visits and more than 3,100 hospitalisations (47% in patients aged over 65 years) for influenza or influenza-like illness.\textsuperscript{15}

- One-third of the growth in NHS emergency admissions to hospital in the winter of 2017-18 was accounted for by patients with flu. Patients with flu generally stay in hospital longer. They are isolated to minimise contagion, affecting patient flow and reducing the flexibility of beds.\textsuperscript{16}

Many of the issues raised by influenza vaccination apply equally to other vaccine-preventable diseases, including pneumococcal disease, tetanus and herpes zoster.

- "In 2014, 17,528 confirmed cases of invasive pneumococcal disease were reported by 28 EU/EFTA countries. The age-specific incidence rate of invasive pneumococcal disease was highest in these aged ≥ 65 years".\textsuperscript{17}

- "The lifetime incidence of herpes zoster is estimated to be about 20 to 30% in the general population, and up to 50% among those living to at least 85 years of age".\textsuperscript{18}

In adopting the Commission’s recommendations for fighting preventable diseases, the Council of the EU acknowledged, “Vaccination is one of the most powerful and cost-effective public health measures developed in the 20th century and remains the main tool for primary prevention of communicable diseases”.

Despite this, there are a number of barriers to uptake of vaccines among adults. ILC research found that over 6.2m "at risk" individuals had not been vaccinated during the 2016/17 influenza season in

\textsuperscript{16}https://improvement.nhs.uk/documents/3202/Winter_review_annex_2.pdf
the UK.\textsuperscript{19} In fact, the UK actually does comparatively well: in a pan-European survey of vaccination coverage, the UK had the highest coverage rates for older adults, close to the EU target of 75\%. The median coverage rate in Europe was 47.1\%. Vaccination is recommended for older age groups in all EU states, but 11 member states were not able to provide figures for coverage.\textsuperscript{20} 
In the following sections, we look at the ways in which technology could potentially overcome these barriers.

\textsuperscript{19}An economic analysis of flu vaccination (2018) International Longevity Centre -UK
Using data better

Barriers to full vaccination coverage that could potentially be overcome by high-performing computers and data analytics:

- Some people do not realise they should have a vaccination.
- Policymakers struggle to engage the "difficult to reach".
- Policymakers do not know what works.
- Adults may not know that their health condition means that they should consider a specific vaccination.

Better use of data opens up possibilities for:

- Better monitoring of vaccination coverage;
- better monitoring of the spread and threat of communicable diseases;
- better identification of target populations for communication.

By the time I've finished this presentation, 6 million tweets will have been posted and there will have been 48 million internet searches. Two billion emails will have been sent. That's Big Data. In the same time – in the next 10 minutes

48 people won't die from a vaccine-preventable disease – because they were vaccinated – but 28 more deaths could have been avoided if we increased vaccination coverage.

So let me ask you, what's the effectiveness of a perfect vaccine that never gets in a patient's arm? Zero.

Dr Michael Greenberg

1. Monitoring vaccination coverage

An Immunisation Information System is a confidential, whole-population, computerised database designed to record all immunisation doses administered to the population. Such systems across Europe show a high variability in frequency of data acquisition, geographical coverage, data storage, and distribution; as such, there is significant potential for improvement in immunisation databases in Europe, as well as worldwide. David Salisbury pointed out that, in the United States, data on seasonal flu vaccination uptake can take two years to become available to policymakers, making vaccination performance-management extremely difficult.
In the UK, data on vaccination uptake is collated every Sunday and is available for policymakers to review by the following Wednesday. This provides for a weekly assessment of the progress of coverage. It is possible to assess whether the service is functioning as well as it should and for policymakers to see the impact of improvements as soon as they are implemented. This data often shows significant variations in vaccination uptake at primary care level. The Department of Health and Social Care uses the data it collects to identify which primary care providers are performing well or badly and to share best practice. The principal challenge for the UK now, as Professor David Salisbury pointed out, is to increase vaccination rates among at-risk groups, such as pregnant women or patients with immune suppression. Still however, more granular data would help.

Figure 1: Provisional seasonal flu vaccine uptake data - weekly snapshot season 2013/14 (comparison with 2012/13 and 2011/12 baseline figures similar stages for flu season)

Much wider use of Immunisation Information Systems and better coordination of these systems at an international level could both track the spread of vaccine-preventable diseases and the success of vaccine coverage globally.
Innovation in action: Twenty-one European countries have developed or are developing systems of digitally recording vaccination information, according to a new ehealth survey by the European Centre for Disease Prevention and Control (ECDC). Five of the systems include automated reminders. The ECDC says these programs can automatically generate lists of under-vaccinated populations, determine which vaccines are overdue, and generate reminders for both doctors and the public.\(^A\)

To be most effective, an immunisation registry should offer ways of identifying at-risk individuals and groups. It should have the capacity to integrate records with clinical and other information, including geography, membership of risk groups, and age. There should also be the capacity to send reminders and prompts for vaccination.

2. Monitoring the spread of disease

Current shortcomings include:

- Traditional disease surveillance systems collect information through healthcare providers rather than directly from individuals; as a result, they fail to catch signals from sick people who may not go to the doctor.
- They are based on case definitions and so may miss emerging diseases with unexpected combinations of symptoms.
- There is a time lag between signals of disease and dissemination of aggregated information.

Big data has the potential to offer a much more efficient system of surveillance of vaccine-preventable diseases – for example, by using data from search engines, where a correlation has been found between search volumes and disease trends.\(^{21}\) Google Flu Trends launched in 2008 to provide an estimate of influenza prevalence in more than 25 countries. Operated by Google.org, the service aggregated Google’s search queries to predict outbreaks of flu using collective intelligence to see patterns that would otherwise be invisible. While Google Flu Trends is no longer publishing, the flu prediction project at the Institute of Cognitive Science Osnabrück has developed a similar model, combining social media with other data to infer the spread of the disease.\(^{22}\)

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\(^{22}\) [https://www.ikw.uni-osnabrueck.de/en/research_groups/neuroinformatics/over-](https://www.ikw.uni-osnabrueck.de/en/research_groups/neuroinformatics/over-
In addition to monitoring web-search, it is possible to look at what users say (rather than what they search for), by monitoring communication patterns and content in discussion groups, blogs and microblogs. Twitter in particular has been found to allow researchers to follow disease trends over time and across areas.²³

Disease surveillance may also benefit from systems that involve active input by users (known as participatory surveillance), using web-based platforms that allow users to provide information about their own health status, such as the crowdsourced influenza surveillance sites Flu Near You²⁴ or Influnet.²⁵

The most thoroughgoing and complex biosurveillance systems aggregate data from a variety of different sources: news sites, web search, social media, crowdsourcing platforms, and official resources such as WHO.

**Innovation in action:** Healthmap, developed by a team of researchers, epidemiologists and software developers at Boston Children’s Hospital in 2006, uses online informal sources to monitor and report disease outbreaks in real time for use by clinicians, policymakers and individuals.²⁸

**Innovation in action:** Break Dengue is an open platform that crowdsources information "on the ground" with a view to accurately predict dengue fever cases around the globe.²⁹

**Innovation in action:** GeoChat is a tool for group communications, based on SMS, email, and Twitter, which has been used in Cambodia. A hotline allows citizens to report disease outbreaks; information is disseminated quickly via GeoChat to clinicians across the country.

3. Identification of target populations

- Helping target resources in locations where low numbers of people have benefited from vaccination;
- Improving reminder systems and delivering targeted communication to healthcare professionals;
- Providing tools for policymakers and manufacturers to assess the benefit-risk of vaccination;
- Ensuring "at risk" groups are aware of the vaccinations for which they are eligible, developing call and recall systems;
- Targeting messaging to people who may particularly benefit from vaccination;
- Helping to identify the reasons why someone might not be vaccinated.

There is the potential, as David Salisbury pointed out, for call-and-recall systems for vaccination to be introduced using GP registers. They can be either age-triggered or seasonally triggered.

There is potential for better exploitation of digital tools to get the vaccination message across.

Since May 2015, the General Data Protection Regulation (GDPR) has put EU citizens in charge of their personal data, including their health data – although at present, in practice, most citizens have limited access to data about their own health. In time, it should become more natural for citizens to check their health and pursue preventative measures such as vaccination. A study carried out on an adult population in Australia found that use of personal health records for immunisation correlates to a higher uptake of influenza vaccination.26

Developments in on-demand printing could result in the development of personalised information leaflets for targeted groups of individuals.

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Innovation in action: The Duke Clinical Research Institute (DCRI) Adult Immunisation Project at Duke University School of Medicine will "analyze data from primary care practices before, during, and after the deployment of educational interventions to determine which approaches were successful in helping patients understand the benefits and risks associated with various vaccinations". Nearly 50,000 US adults die each year from vaccine-preventable diseases, largely because adult vaccination rates lag well behind national goals, particularly for high-risk groups. Big data offers the potential to understand which interventions work with these groups.

Innovation in action: Text messages and computerised reminders have been shown in some studies to improve adherence to vaccination schedules.

Discussion

There was recognition at the meeting that policymakers face challenges when it comes to collecting, storing and using data on people's health. Privacy and misuse of data are growing public concerns. Google Flu Trends sought to avoid violations of privacy by aggregating millions of search queries; even so, at the time some objectors questioned whether "user-specific investigations could be compelled", even potentially against Google's wishes.

While we should not underestimate the significance of the challenges that data collection storage and security present, Dr Michael Greenberg argued that "the big bottleneck is the lack of understanding about how best to use big data."

Ideas from the workshop:

- Interactive infection maps to help people understand their risks of infection;
- Information campaigns tailored to personal data;
- Online ads from the health service targeted by location with a focus on areas with low uptake;
- Mobile technology plus location data could remind us when and where we can be vaccinated;
- SMS, email and telephone reminders targeted at adults;
• Electronic Health Record owned by the user, with information about vaccination status;
• Vaccination incorporated into other healthcare apps;
• Immunisation and other health information to be provided alongside online government information on pensions;
• Online portals could allow people to be aware of their eligibility for vaccinations and keep track of their vaccination history;
• An online risk calculator would help people understand their risk of infectious diseases.

Policy directions:
• Regulation should ensure data privacy.
• Policymakers should ensure that individuals own their own data.
• Policymakers should ensure common data standards.
• There is a need for more and better data collection.
• There is a need to ensure government data is integrated across different platforms.
• There would be a benefit from centralising immunisation records.
• It is important to ensure data systems "talk to each other" (so information is shared between my GP and the pharmacist who vaccinates me).
The internet

“If information is power and the internet is information, the internet is power” Philip Weis, Chairman, ZN Consulting

Barriers to vaccination coverage that the internet can help to address:

- In an era of fake news, people sometimes find it difficult to know where to go for accurate information. There was a feeling in the workshop that anti-vaxxers have been allowed to take the initiative online. Social media has been used to spread disinformation. Fake stories spread via WhatsApp have been accused of risking progress
on vaccinating against yellow fever in Brazil\textsuperscript{27} and polio\textsuperscript{28} and measles in India.\textsuperscript{29}

- Professor Pier Luigi Loalco highlighted the challenges in Italy over the past five years. He pointed out that, by April 2015, there was a "lot of anti-vaccination material on Facebook and little positive material." One participant felt that up until about 2013 the vast majority of messages about immunisation on YouTube were negative.

- "The levels of mistrust about vaccination are increasing," said Isabel De La Mata Barranco of the European Commission. "In some countries, 40\% of the population think vaccination is not safe or not needed. If our citizens think vaccination is unsafe, this is a fundamental problem for our healthcare systems."

- The belief by some that flu is not a serious disease does not help trust levels when it comes to vaccination. There is a need for better, more targeted information.

- Many healthcare professionals are not themselves immunised: Isabel De La Mata Barranco pointed out that a number of measles cases in the current outbreak occurred among healthcare professionals. There was a feeling that if they had not been convinced, members of the public were unlikely to be persuaded. Trust campaigns could begin by targeting them.

- "Our first battle must be to improve trust," said Eleanor Gentile MEP. "Every day, we are faced with more fake news and people don’t know what to believe and what to not believe. We live in a time of fear and mistrust and we must find a way to give people something they can trust. Technology might help here."

- Philip Weis, Chairman of ZN Consulting, argued that without better use of social media by the vaccination community, "black swan" events\textsuperscript{30} (rare, hard-to-predict events of large magnitude and extreme effect) would be increasingly likely: "anti-vaccinators are sometimes more sophisticated and coordinated than those advocating pro-science messaging."

\textsuperscript{27} https://www.wired.com/story/when-whatsapp's-fake-news-problem-threatens-public-health/

\textsuperscript{28} https://www.ibtimes.co.in/tamil-nadu-fake-anti-vaccination-messages-circulated-widely-whatsapp-facebook-fuelling-fears-713902

\textsuperscript{29} https://www.wsj.com/articles/whatsapp-users-spread-antivaccine-rumors-in-india-11555153203

\textsuperscript{30} https://en.wikipedia.org/wiki/Black_swan_theory
• One study of attitudes to influenza vaccine on social media found that there is a commonly observed echo chamber effect – hearing what you already believe and are biased towards – which has particularly problematic consequences when it comes to vaccination. Those who are persuaded to reject vaccination tend to form real-world, as well as online, communities, leading to clusters of unprotected individuals and greatly increasing the likelihood of outbreaks of disease.\(^{31}\)

![Tweet by Donald J. Trump](https://twitter.com/realDonaldTrump/status/449610915411196161)

Healthy young child goes to doctor, gets pumped with massive shot of many vaccines, doesn't feel good and changes - AUTISM. Many such cases!

<table>
<thead>
<tr>
<th>RETWEETS</th>
<th>LIKES</th>
</tr>
</thead>
<tbody>
<tr>
<td>11,170</td>
<td>8,815</td>
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</table>

5:35 AM - 28 Mar 2014

The internet is the most comprehensive source of information on health and vaccination and has the potential to help boost vaccination coverage by disseminating trustworthy and valid information. As the tweet above shows, however, there is also the potential for far-reaching campaigns of malign or (to put it politely) muddled messaging. There was recognition at the workshop of a need to use the tools of the internet to counter the propaganda of anti-vaxxers.

What approaches are needed?

**Data mining**
It has been found that parents seeking vaccine information on the web (compared to those using other sources of information) are less likely to recognise the benefits of vaccination.³² The monitoring of vaccine-confidence as reflected in internet activity might help to intercept negative trends and enable a response.

**Online engagement**
There was a feeling that vaccine advocates needed to be present and active online - not simply responding but leading the argument. Policymakers should explore innovative ways of communicating offered by new tools. "We don't know how to communicate health messages," said Isabel De La Mata Barranco. "We need to explore new ways of communicating with the public, and we need new ways of presenting information."

Facebook, for example, presents a particular opportunity when it comes to reaching older people:

- There are 2.2bn users on Facebook. In the UK, the over-65s are the fastest growing demographic user group (albeit from a low base), followed by those aged 50-64.³³
- "Facebook is a very cost-effective way of reaching a targeted audience of older people", participant in the futures workshop.

**What is happening?**
Evidence presented at the workshop suggested that, despite a slow start, the scientific and policy community is beginning to get better at online engagement regarding vaccinations.

- The WHO has set up the Vaccine Safety Network to accredit websites dealing with vaccination according to certain quality criteria, which ought to make it easier for users to judge the provenance of what they are seeing.
- In response to disinformation, a small group of doctors across the world are using social media to get positive messages out:

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• Romanian paediatrician Dr Craiu Mihai, concerned by rising numbers of measles cases in Romania and the volume of online anti-vaccination propaganda, set up a Facebook page (https://www.facebook.com/drCraiuMihai/) where he posts positive messages about vaccination. The page has been liked more than 120,000 times and some of his videos have been viewed more than half a million times.

• Roberto Burioni, a Professor of Microbiology and Virology from Milan, is an active and outspoken social media campaigner against anti-vaxxers. His pro-science Facebook posts can reach 3-4 million people. His page has nearly half a million likes, and he has more than 86,000 followers on twitter.

• The Reddit r/vaxxhappened (https://www.reddit.com/r/vaxxhappened/) claims to "collect the outrageous and dangerous tales told by dim-witted anti-vaxxers on all forms of media... We are pro-vaccination because we're civilised. And not stupid." The group has grown to around 90,000 subscribers.

• In Italy, the National Federation of Physicians, Surgeons and Dentists (FNOMCeO) has launched a website called "Doctor, is it true that..." (https://dottoremaeveroche.it/chi-siamo/) alongside an offline shock poster campaign, Always ask the doctor (Chiedete sempre al medico), to counter fake news. Citizens can ask questions about vaccination and the answers are posted on the site, which is building up an archive of resources.

• NHS England’s #flufighter campaign combines online and offline material with a social media hashtag to get out messages about the value of vaccination.34

34http://www.nhsemployers.org/flufighter
How can we improve online communications about vaccination?

1. Walk in the shoes of the patient
2. Invent new communication models
3. Join online conversations: “Tweet accurate information and challenge #fakenews; Experiment with new tools (Snapchat and Instagram as well as Facebook and Youtube); Embrace networks and patient communities.”

Philip Weis, Chairman, ZN Consulting

Discussion

Discussion at the workshop centred around the sophistication of the anti-vaxxers. There was a feeling that the scientific and policymaking communities have been slow to respond and as a result have struggled to catch up. There was a desire to respond deftly and to deploy technological tools with similar effectiveness, using all the technology available.

There was concern that rebuttal and refutation of anti-vaccine propaganda gets lost in the online noise. “People want information about vaccination but have never been asked about their concerns,” said Peggy Maguire. “We need to build health literacy to develop a vaccine-aware public.” There was a feeling that it was perhaps not enough simply to tell people what is good for them; there is a need to engage them emotionally.

Our experts felt that there was limited evidence about “what works” in terms of online engagement. One participant pointed out the need to experiment, saying, “We have to break models, do some trial-and-error-pilots to see what works”.

Participants also highlighted a lack of access to technology among some older people and a relative lack of skills, which could potentially mean that digital exclusion could lead to health exclusion.

Ideas from the workshop:

- A vaccination-awareness day advertised on Facebook;
- An app for parents to ask questions anonymously of doctors or other specialists;
- Instagram influencers to address adult immunisation;
• Use new technologies to help engage healthcare workers;
• Use of social media to spread good stories about vaccination.
• Social media advertisements for local pharmacies;
• An Instagram contest could showcase adults who have been vaccinated, explaining why they do so.

**Policy directions:**
• Governments and industry should invest in digital health literacy.
• It is important to accredit accurate information and reassure people of the reliability of information.
• Policymakers and the health community should invest in good communications to tackle "fake news".
• Health leaders and governments should support independent "fast fact" charities quickly rebutting fake news.
The internet of things

The growing ubiquity of connectivity in daily life offers the opportunity to overcome some of the barriers to vaccination:

- Some adults may not keep a good record of their vaccination history and may not know when they are due for a vaccination.
- Even though older adults are increasingly digitally engaged, some older people are digitally excluded by current forms of connectivity, and this was felt by participants at the workshop to be one of the most significant barriers to relying on technology to improve uptake of vaccinations. Not all older people have a smartphone or know how to use it, as one participant pointed out.

Connecting our homes, cities and even ourselves to the internet will offer increasing opportunities for improving access to health services. Business Insider predicted that by 2022, 10% of the world’s population will be wearing wearable devices. These may offer the possibility of technology that is less complicated at the user end and more intuitive.

Innovation in action: In India, a medical student called Richit Nagar, shocked by the statistic that half a million children die from vaccine-preventable diseases in the country each year, devised a digital necklace. The necklace is a medallion on a black thread (culturally important as a powerful symbol of protection, a reminder that technology works best when it is not imposed randomly but when it integrates with people’s lives).

The necklace stores medical history, including vaccination records. When healthcare workers visit a village, they can easily scan, read and update the information using a smartphone. The necklace has been found to be five times less likely to be lost at home than paper records and has increased uptake of vaccination.\

Much will depend on how the internet of things develops, but wearables and home-based technology have the potential to be more inclusive than purely text-based technology.

Wearable devices could help monitor health and remind us if we need a vaccination.
Smart packaging could connect with electronic health records when a vaccination is delivered.

3D printing could lead to improved delivery of vaccinations, lower costs of production and increased access. Geneticist Craig Venter is working on the potential for medicines and biological structures to be created in digital form, emailed to wherever they are needed, and produced using local 3D technology.35

**Discussion**

Again, issues of privacy were at the forefront. There was also discussion of digital exclusion, reflecting concern that older people may be slower to take up new technology: “Older people are sometimes ignorant of the potential of new technology,” one participant said.

In some parts of Europe, older people are more likely to live in rural areas where digital coverage may not be as good and opportunities for seizing the potential of the internet of things are lower.

There were also questions about costs, with the concern that innovations may not engage the “hard to reach” despite the fact that they may benefit from them particularly.

Anxiety was expressed that if technology bypasses healthcare workers, this may again impact detrimentally on older people, who may be more reliant on personal contact.

**Ideas from the workshop:**

- A virtual lifelong personal assistant that would, among other things, give advice on health behaviour and remind us of the need for regular screenings;
- Wearable technology to measure our vital signs and signal when something is not normal – or when we are in need of a vaccination;
- An ultraviolet barcode on our skin could hold our healthcare data;
- Location-based alerts could prompt people in at-risk groups when they are near a place where they can receive a vaccination;

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• Siri, Alexa and Google Home could book vaccination appointments;

• Smart home technology could remind us to vaccinate ourselves.

**Policy directions:**

• Government, industry and public health experts should properly evaluate what works.

• Health care providers and policymakers should ensure patients are central to solutions.

• Government and the private and voluntary sector should issue technology to older people and train them to evaluate their own health.

• Policymakers should find a way to support lifelong e-learning to tackle the challenges both of digital exclusion and poor health.
Gamification

Gamification ("the process of adding games or gamelike elements to something – such as a task - so as to encourage participation"36) offers the potential to overcome the following barriers:

• People may not understand the dangers of vaccine-preventable diseases.
• They may not realise that they should be vaccinated.
• They may be resistant to the idea of vaccination.

Games use different and novel methods to engage people through stories, immersion, fantasy, design and gameplay that involve the imagination and the emotions as well as the intellect.

There is emerging evidence that games can make a difference to how people feel about vaccination. A randomised controlled trial targeting parents and children in Italy explored the effect of smartphone apps incorporating gamification on knowledge about MMR (measles/mumps/rubella) and the likelihood of vaccination. The researchers found that those who received the intervention were significantly more likely to intend to vaccinate. The researchers argued that: "Parent-centered, gamified mobile interventions aimed at providing parents with vaccination-related information can be used to increase their knowledge and their intention to vaccinate as well as their confidence in the vaccination decision".37

**Innovation in action:** The game, Plague Inc., simulates the spread of an infectious disease; the player must attempt to control (and encourage) its spread. The Centre for Disease Control and Prevention in the US has said the game “uses a non-traditional route to raise public awareness on epidemiology, disease transmission, and diseases/pandemic information. The game creates a compelling world that engages the public on serious public health topics”. G

36 https://www.merriam-webster.com/dictionary/gamification
37 Marta Fadda, Elisa Galimberti, Maddalena Fiordelli, Luisa Romanò, Alessandro Zanetti & Peter J. Schulz (2017) Effectiveness of a smartphone app to increase parents' knowledge and empowerment in the MMR vaccination decision: A randomized controlled trial, Human Vaccines & Immunotherapeutics, 13:11, 2512-2521, DOI: 10.1080/21645515.2017.1360456
**Innovation in action:** An online Fake News Game from the University of Cambridge puts "players in the shoes of an aspiring propagandist, to give the public a taste of the techniques and motivations behind the spread of disinformation — potentially 'inoculating' them against the influence of so-called fake news in the process!"

**Innovation in action:** Vax Pack Hero from The Children's Hospital of Philadelphia teaches the history of vaccination while having the user fight up to 21 different vaccine-preventable diseases.

**Discussion**

One group of researchers has argued that there is limited evidence of games improving health, since there has not yet been rigorous evaluation (not least because very few health apps yet include gamification).

Such discussion as there has been of gamification for health has tended to focus on children. There was some discussion about whether adults were interested in games in the same way and, if so, what incentives and rewards would look like for adults.

Again, there was concern that older adults have different attitudes to technology and that this, combined with cost (someone pointed out that virtual reality is expensive), might make this a less cost-efficient approach to increasing vaccination coverage, certainly in the short term.

**Ideas from the workshop:**

- Games targeted at children to educate them about the value of vaccination;
- Gamification apps to encourage vaccination through competition;
- A VR headset game for children: see a doctor saving the world by getting or giving an injection;
- Immersive virtual reality could help people realise the impact of serious diseases;
- Games that appeal on an emotional level, thus providing a more powerful counter to anti-vaxxers' (often emotionally-focused) propaganda.

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The sharing economy

The sharing economy is often defined as an economic model enabled by peer-to-peer acquisition, provision, or sharing of goods and services through an online community platform.

Potential barriers the sharing economy could help to overcome:

- Some people might find it difficult to get to a place where they can be vaccinated.
- They may lack information about vaccination.
- They may not appreciate that they are eligible.

The sharing economy could make vaccination more accessible through shared transport services.

Sharing economy platforms could provide a community hub for the sharing of information about adult vaccination – see for example PatientsLikeMe.39

Sharing platforms could provide a quick and reliable route to a qualified practitioner.

**Innovation in action:** US-based healthcare transport company, Circulation, leverages ride-sharing services such as Uber and Lyft to take patients to healthcare appointments.

**Innovation in action:** In October 2016, Uber offered free, on-demand flu vaccination in more than 35 US cities, with care packages including a water bottle, tissues, hand sanitiser, tote bag and lollipop.

**Innovation in action:** The UberHealth service, launched in 2014 (and relaunched in 2018), allows US users to request a nurse to visit them wherever they are to administer the vaccination. The service usually costs 10 USD and nurses can immunise up to 10 people per visit. On 25 October 2015, between 11:00 and 15:00, the service was free.

39 https://www.patientslikeme.com/
**Innovation in action:** Pager.com allows users in New York, Florida, Texas and New Jersey to see a doctor within two hours in the patient's own home, if needed. It also offers an interactive session (chat, voice or video) with a doctor or nurse, plus a scheduling app to book an appointment with your own doctor, which the developers of Pager liken to Open Table (the restaurant-booking app) for doctors.

**Discussion**
The sharing economy has undermined funding and delivery of existing models in other fields, and there was concern that it could do so here, with the added disadvantage that it could be a force for decentralisation. Policymakers are conscious of a need for more collaboration and exchange of information about vaccination, and for more coordinated initiatives. There was also the question of whether such services, while convenient for users, were sustainable at scale. Are these sharing economy initiatives destined to be an add-on, simply providing an additional means of transport and vaccine delivery?

**Policy directions:**
- Policymakers should support better interdisciplinary communication and collaboration.
AI and robots
Robots offer the potential to overcome the following barriers:
• Some patients are scared of the needle.
• Some patients may not appreciate that they are eligible for vaccination.

AI (machine learning) more broadly offers the potential to overcome:
• Lack of useful data available to healthcare workers and policymakers;
• Lack of clarity about how best to target information;
• Flu strains are constantly mutating, leading patients to be less certain about the nature and progress of the disease and therefore the value of vaccination.

In some countries, there are no systems to identify at-risk individuals or to target them. The use of AI combined with better data offers the opportunity to speed up the process of identifying people who would benefit most urgently from vaccination and reaching them in a personalised way.

"Pharmaceutical companies are increasingly embracing the potential of AI to identify drug targets, new uses for existing drugs, or to secure faster approval of medicines" – Sarah Neville, FT.40

Sanofi and Berg will use AI to assess "different populations, races, different ages, different geographies" to gauge whether certain vaccines are more effective in "say Asia versus Africa versus the US or the UK". John Shiver, Senior Vice President of R&D for vaccines at Sanofi says: "We are hoping this will get us closer to the next generation of influenza vaccine".41

Robots
Humanoid robots have the potential to distract patients from pain.
An immersive experience using robots and/or virtual reality could distract and calm fears, with the potential to reduce pain and reduce fears, increasing the immune response.
Robots can help deliver vaccinations promptly to individuals and pharmacies.

40Sarah Neville, Financial Times, October 30, 2017 [https://www.ft.com/content/a2c-c8f54-bd47-11e7-9836-b25f8adaa111]
41Sanofi turns to artificial intelligence to beat flu - Financial Times
Robotics could help make manufacturing processes more efficient, bringing down the cost of vaccines.

**Innovation in action:** In Vanautu, where many of the 80 or so islands that make up the nation have no airstrips or good roads, drones are now being used to deliver vaccinations.

**Innovation in action:** Doctors are exploring the use of robots to distract children from the pain of vaccination. 86% of the children in the trial said they would like the robot to be present at such a procedure in the future.

**Discussion**
There was a feeling that the science is as yet underdeveloped, and it is hard to know how robotics will make an impact in this aspect of healthcare. AI raises the usual questions of privacy, perhaps somewhat intensified by the feeling that individuals’ data is being “worked on” in ways they have no capacity to understand.

**Ideas from the workshop:**
- A robot carer could help remind when vaccinations are due.
- Bots could have conversations with people about their concerns.
- A virtual lifelong personal assistant that would, among other things, give advice on health behaviour and remind us of the need for regular screenings.
Blockchain

Barriers:

• The desire for greater sharing and transparency of health data raises questions of privacy, identified by participants at the workshop. These questions have been a major impediment to the introduction of electronic patient records, with policymakers appearing reluctant to grapple with the politics of digitising personal information and making it more freely available.

• Some adults may be worried about the provenance of information: what to believe about vaccination in a world of fake news?

• Vaccines may go to waste because of inefficiencies in the supply chain, consequently increasing the cost of vaccines for healthcare providers.

Blockchain – a shared, immutable record of transactions built from linked blocks and stored in a digital ledger – offers the possibility of overcoming these barriers in the following ways.

Blockchain could ensure that medical records are up-to-date, accurate and, where they need to be, private, allowing for more confident use and sharing of health information.

Electronic health records that are genuinely secure could put greater power into the hands of individuals to make informed decisions about their health.

Blockchain tools could give people more confidence in the authority of online information about vaccination to counter fake news spread (for example) by bots.

Blockchain can monitor the supply chain and identify where the process breaks down – as a result of improper storage conditions or damaged or tampered packaging, for example. This will not only have the immediate effect of ensuring that vaccines are delivered effectively but in the longer term also serve to improve vaccine confidence.
Innovation in action: Blockchain could improve supply-chain-management and reduce the cost of delivering adult vaccinations. A blog for the World Bank claimed that the technology could increase efficiency, maintain quality and reduce costs as well as delivering improvements in real time.\textsuperscript{N}

Innovation in action: Medicalchain and Groves Medical Group are beginning to pilot a blockchain platform for patients. Medicalchain uses blockchain technology to facilitate the "transparent exchange of medical records by patients and doctors".\textsuperscript{O}

Innovation in action: ImmunoTracker is a digital blockchain-based solution developed in a hackathon for the UAE government, which makes vaccination records and in the future all health-related records secure yet accessible and reliable. The app seeks to ensure citizens stay informed and up-to-date regarding their vaccinations and allows medical professionals and authorities to share important immunisation data in real time, without compromising privacy.\textsuperscript{P}

Innovation in action: Statwig combines blockchain technology with sensors to automate product tracking and ensure that data is reliable, ensuring that vaccines do not go to waste because of mismanagement of the supply chain and that vaccines that are delivered have been temperature-controlled and monitored.\textsuperscript{Q}

Discussion
There was concern that blockchain technology might – at least initially – be developed by private healthcare services, with the potential to increase social inequalities.

While it is widely accepted that blockchain technology offers security and traceability, getting this message across to a sometimes tech-sceptical audience was seen to be difficult because the technology is complex and hard to explain in simple terms.
Materials science

Barriers:

- Some people are deterred from taking up vaccination because of fear of the needle: needle phobia is thought to affect 10% of the population.\(^4^2\)
- Some people are not aware of the need to be vaccinated.

Materials science can help address fear of the needle by developing alternative ways of delivering vaccines – oral, nasal or through a nanopatch, for example.

Graphene could offer the potential for new and better monitoring devices or sensors: a graphene-based tattoo has been developed at the University of Texas that is capable of monitoring health.\(^4^2\)

Innovation in action: Mark Kendall from the University of Queensland is developing a postage-stamp sized nanopatch with thousands upon thousands of tiny spikes on its surface (approximately the width of a human hair and invisible to the naked eye, but long enough to breach the outermost layer of skin), which could be used as an alternative to the needle for delivering vaccination.\(^R\)

\(^{42}\)https://www.guysandstthomas.nhs.uk/resources/patient-information/all-patients/overcoming-your-fear-of-needles.pdf
\(^{43}\)https://www.bbc.co.uk/news/av/technology-41669803/how-a-graphene-tattoo-could-monitor-your-health
Recommendations

We welcome the recently announced EU initiatives on vaccination and digital health and are keen to work with the Commission and member states on implementation.

ILC recommendations:

• Big data should be much more extensively used to monitor disease spread, review vaccination coverage, and identify target populations for reminders and messaging. There is a need to work towards greater consistency of data collection and shared platforms across countries to ensure sharing across borders, in real time, throughout Europe and globally. There is a need to leverage big data and specific platforms to target messaging to those who would benefit most. None of this comes without political complications to do with privacy, and there is urgent need for government to engage with privacy issues, encourage debate, and convey to citizens the life-and-death implications of collecting and sharing information about vaccine-preventable disease.

• The internet has been used to spread fake news, and there is a need now to use the internet to counter it. This will require an imaginative, rather than purely scientific response, engaging people emotionally as well as rationally. The scientific and policy communities have been slow to start, and there is not yet clear evidence about what works with which groups, so there is an urgent need to experiment with different ways of reaching people and to assess which are effective.

• Government should support initiatives to ratify information as reliable or penalise it for being untrue, such as the WHO’s Vaccine Safety Network accreditation. This is part of a larger discussion about the state’s responsibility for sanctions against information that is directly misleading. How much authority the state can or wishes to exercise is an urgent question for governments in light of the potential of fake information to lead to pandemics and high public health costs.
Use of technology to improve vaccination uptake should start from the point of view of the patient and in particular those who suffer from social inequalities that often lead to digital exclusion. The introduction of technological solutions should not exacerbate existing inequalities or create new ones.

It is not clear what emerging technologies (gamification, robotics) could be central to improving vaccination uptake rather than interesting byways. Not all technological advances will be equally useful. There is a need to invest in emerging technologies while at the same time taking a rigorous approach to effectiveness.

Based on the discussions and the ideas that emerged during the futures workshop, ILC believe that policymakers should focus on:

1. Delivering a policy framework that will support innovation
2. Regulation to support innovation
3. Taking a life-course approach to immunisation

**1. Deliver a policy framework that will support innovation**

**European Policymakers should:**

- Develop a specific funding programme on "what works" to ensure that policy and financial investment in technology delivers its potential;
- Ensure that Europe has a research environment and capacity that helps it to lead the world in innovation. This requires investment in skills, as well as direct funding of research;
- Support innovation that focuses on those most in need and attempts to reduce rather than enlarge inequalities.

**2. Regulate to support innovation**

**European Policymakers should:**

- Legislate to ensure that products and services are accessible and usable for all ages and abilities;
- Ensure innovation is not hindered by data protection rules or other regulation while supporting a move towards individual ownership of data;
- Use regulation to improve trust in data use for better health outcomes, including regulating to ensure ownership of data by the individual.
3. Take a lifecourse approach to vaccination

**European Policymakers should:**

- Recognise the challenges of demographic change and ageing populations and ensure policy supports vaccination as important across our lives. Develop an EU wide programme of action to encourage uptake of adult as well as child immunisation;

- Focus policy attention on adults in at-risk groups as well as older people;

- Support growing financial investment in the prevention of ill health across our lives.

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**We want a new vision for the modernisation of health. We must stop treating health simply as a cost: we must invest in it.**

**Elena Gentile MEP**
Innovation in action references

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