

Patient and public involvement in EAVE II: the first two years

Early Pandemic Evaluation and Enhanced Surveillance of COVID-19



THE UNIVERSITY of EDINBURGH



Collated by Dr Lana Woolford on behalf of the EAVE II Public Advisory Group

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About EAVE II

The Early Pandemic Evaluation and Enhanced Surveillance (EAVE II) project was first set up to track the COVID-19 pandemic and vaccine effectiveness for people in Scotland, by using routinely collected health data.

Led by the Usher Institute at the University of Edinburgh, the project is a collaboration with the Universities of St Andrews, Strathclyde, Aberdeen and Glasgow; Public Health Scotland; the School of Health at the Victoria University of Wellington; and the West of Scotland Specialist Virology Centre.



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The research team includes data analysts, epidemiologists, project managers, administrators, public health specialists, patients, clinicians and members of the public. Our regular patient and public involvement (PPI) contributors form a Public Advisory Group (PAG) which helps to shape the evidence base for COVID-19 in Scotland, the UK and beyond. We also collaborate with other patient groups and support charities to carry out our work, including Long Covid Scotland and the Stillbirth and Neonatal Death Society (Sands).

An integral part of this forum, our PAG and external PPI contributors help to embed the lived experience of the public into our research about the COVID-19 pandemic, which has changed the life of so many.



LONG COVID
SCOTLAND



Foreword



“EAVE II is a unique collaboration between Public Health Scotland, researchers across Scottish universities and members of the public. We use health data, routinely collected from the public, to provide rapid evidence for policy makers to inform responses to the ongoing COVID-19 pandemic.

Working meaningfully alongside patients and the public is at the core of our work. Bridging the gap between the pandemic experiences of people in Scotland, and the data we analyse, helps to ensure that the evidence we offer is relevant, understandable, acceptable and accountable to real people in real world settings.

Although carried out for public benefit, the day-to-day work of the EAVE II Public Advisory Group can often go unseen to public audiences. This report offers an account of their involvement over the first two years of EAVE II, and our hopes for working together both in relation to the ongoing pandemic and pandemic preparedness.”

Professor Sir Aziz Sheikh

OBE FRSE FMedSci | Principal Investigator for EAVE II

With thanks to our funders

EAVE II is funded by the Medical Research Council, National Institute for Health Research, Health Data Research UK and the HDR UK BREATHE Hub, Public Health Scotland, and National Core Studies. It is supported by Scottish Government and University of Edinburgh.





Executive summary

The EAVE II project was set up to track the COVID-19 pandemic and vaccines in Scotland, collaborating with Public Health Scotland and other research institutions to do so. The team informs policy across the UK and globally. We use routinely collected health data from 99% of the Scottish population to provide insights into COVID-19 deaths and hospital admissions; pandemic healthcare disruption; vaccine uptake, safety and effectiveness; immune responses to vaccines at a population level; and much more.

Patient and public involvement is organised through the central EAVE II Public Advisory Group (PAG), made up of a wide range of patient and public contributors across Scotland, England and Wales. The PAG is represented on the EAVE II Steering Group, and works with other PPI contributors to incorporate relevant lived experience on specific analyses.

The PAG have contributed to grant development, analysis design, project steering, analysis interpretation, dissemination and evaluation of EAVE II research. The Group have enjoyed undertaking a variety of valued work, actively creating an impact in the project, and working in a collegiate manner with both PPI and research-facing colleagues. Members of staff attached to the EAVE II project feel that the PAG has had a genuine impact on the quality and relevance of their work.

Working from a foundation of contributions to research design, they would like to see data projects which build on the meaningful PPI and seeds of co-production seen in EAVE II, as well as a greater emphasis on PPI training and development for contributors and researchers alike.

The National Institute for Health Research (NIHR) defines Patient and Public Involvement (PPI) as:

“research done with or by patients and the public, not about, to, or for them.”

This report outlines the PPI work carried out by the PAG and project staff. We seek to:

- **provide context about the wider project**
- **highlight PPI activities, and their impact, carried out in a health data context**
- **reflect on PPI work carried out so far, including successes and challenges**
- **provide suggestions for PPI in future ‘pandemic preparedness’ settings.**

Involving patients and the public in near real-time pandemic tracking

EAVE II was originally funded in March 2020 as an 18-month project to track the COVID-19 pandemic as it unfolded in Scotland. The study also planned to look at the effectiveness of vaccines ‘in real life’, as soon as they were found safe and effective in clinical trials.

This research is based on public health data related to the pandemic, and contributes evidence to COVID-19 policy-making in Scotland, the UK and beyond.

Patient and public involvement (PPI) is a key part of all medical research, and helps to make it relevant, understandable, accessible, acceptable and accountable to the people it will affect.

The COVID-19 pandemic, and the medical interventions that followed, have had the widest-ranging impacts of any public health crisis in recent history. We feel this makes PPI even more important.

The Public Advisory Group (PAG) was set up to enable patients and the public to shape and contribute to research alongside EAVE II and Public Health Scotland (PHS) staff, throughout the project.

As with the research itself, PPI contributors and plans have had to adapt and respond rapidly to the pandemic situation, which brought new and sometimes unexpected challenges on a monthly or weekly basis.

What is the EAVE II project?

The full name of the EAVE II study is **Early Pandemic Evaluation and Enhanced Surveillance of COVID-19**.

It is based on an earlier project called 'EAVE' - **Early Estimation of Vaccine and Anti-Viral Effectiveness**. This was the first study in the world to look at how well vaccinations worked at a national level. The analysis was carried out for **227,000 people in Scotland during the 2009-2010 swine flu pandemic**.

EAVE II builds on that work and applies it to the current COVID-19 pandemic, caused by the severe acute respiratory syndrome-related coronavirus (SARS-CoV-2). The project was first set up to:

1. Track the COVID-19 pandemic in Scotland;
2. Identify population groups most at risk from SARS-COV-2 infection and COVID-19 death;
3. Monitor the effectiveness and safety of population-wide vaccination.

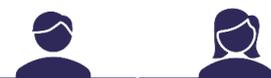
To do this, the EAVE II team worked with Public Health Scotland (PHS) to expand the original EAVE dataset, or 'cohort', from 227,000 to 5.4 million people registered with a GP in Scotland, representing 99% of the population.

This is updated almost in real time, which has allowed the team to answer urgent research and policy questions throughout the pandemic.

Data in EAVE II

GP surgeries in Scotland work with a trusted third party healthcare software provider to add data into the EAVE II cohort. This data is de-identified, which means that our research team cannot see, or identify, individual people.

What doctors and nurses see



	Jose Estefan	Amy McDonald
D.O.B.	01-01-1990	02-02-1980
Postcode	EH7 2MT	EH1 8JK
Sex	Male	Female
Date admitted	01-05-2021	10-05-2021
Tests done	Blood test	X-ray
Diagnosis	Infection	Broken toe

What certified researchers see



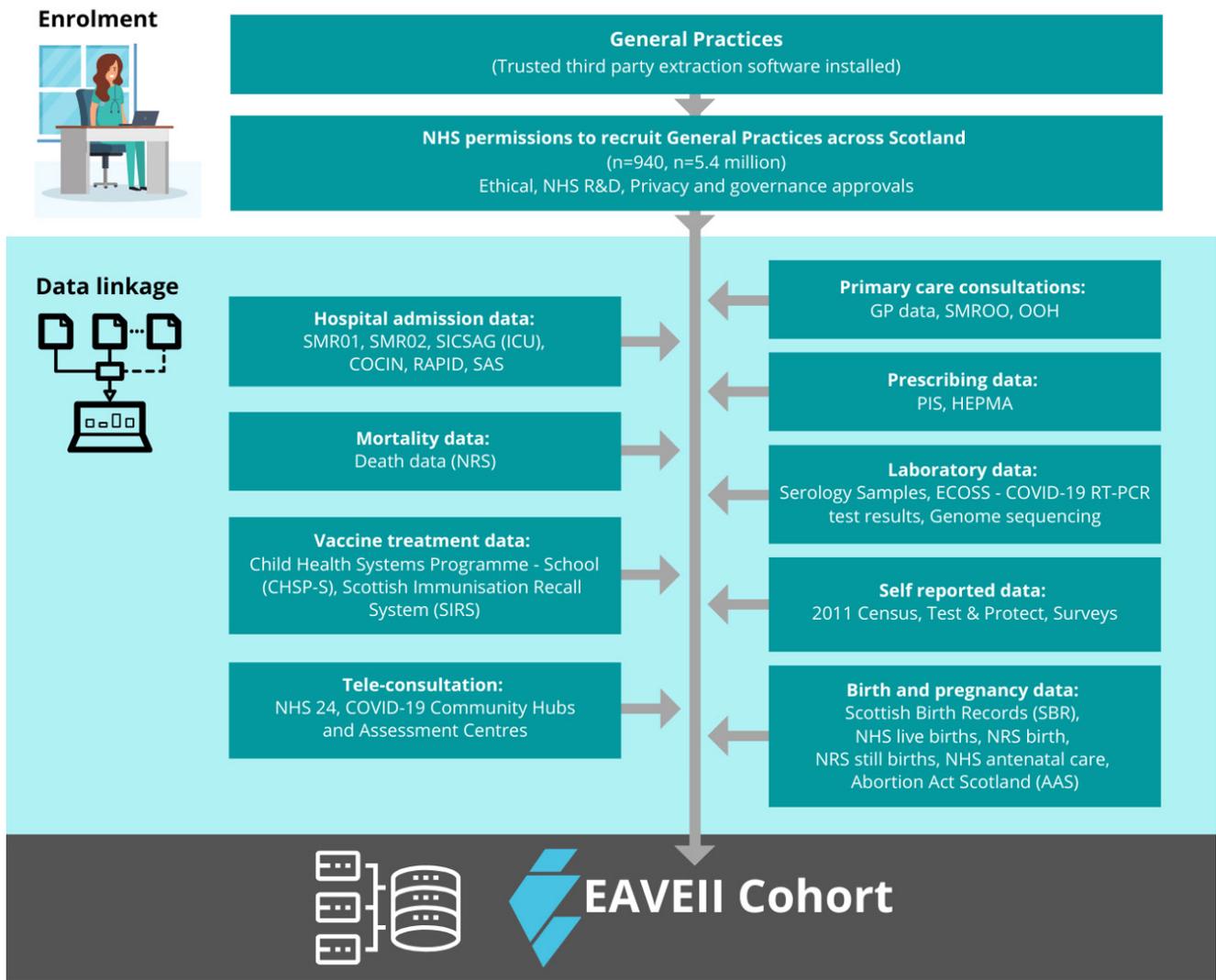
	Patient 1	Patient 2
D.O.B.	XX-XX-1990	XX-XX-1980
Postcode	XXX XXX	XXX XXX
Sex	Male	Female
Date admitted	01-05-2021	10-05-2021
Tests done	Blood test	X-ray
Diagnosis	Infection	Broken toe

A simplified example of what de-identified data looks like for researchers.

Each new analysis is approved by a Research Ethics Committee, NHS Research & Development, a Patient Benefit and Privacy Panel, and other governance structures. We also work with our PPI contributors to ensure that the research is relevant and transparent

to the public.

Data from people’s GP records are linked to other data using a Community Health Index (CHI) number unique to each person in Scotland.



Data sources used in EAVE II.
See Glossary for details.

Research in EAVE II

To date, the EAVE II team have provided rapid evidence to eight different decision-making bodies including the Scottish Government, World Health Organization (WHO), Joint Committee on Vaccination and Immunisation (JCVI) and the Scientific Advisory Group for Emergencies (SAGE).

This includes world-leading studies on vaccines; healthcare disruption; the impact of new variants; and COVID-19 during pregnancy and in people with multiple health conditions. New projects continue to develop on Long Covid; variations in immune responses; and new treatments for COVID-19.

Founding the Public Advisory Group

The Public Advisory Group (PAG) has evolved into a key pillar of the EAVE II team and project, working alongside research, management and public health staff to shape the project as it moves forward.

The Group and its activities have expanded over time, from a smaller team reviewing key outputs to a forum of 15 public contributors involved in analysis design and writing public-facing materials.

Members of the PAG were first recruited in October 2020, once all the appropriate governance structures were in place and funding had been set aside to recognise PPI contributors appropriately for their time. The rapid response needed for EAVE II did mean

that public contributors were, unfortunately, not able to shape the earliest work of the project. Key research questions were largely set by policy-makers in response to urgent public health needs at this stage.

Recruitment

Recognising the need to have public and patient representation embedded in decision-making structures, we set up two roles; one for PAG Members and another for PAG Co-Leads, who are part of the EAVE II Steering Group.

The Co-Leads have equal standing with remaining members, and represent the PAG, facilitating dialogue between the PAG and Steering Group. Our Co-Leads were chosen on the basis of the extent, and variation, of their PPI experience, personal background, and approach to PPI.

The format of in-depth PAG discussion and Steering Group representation has been established over time by Usher Institute staff and PPI contributors as a balanced structure which enables meaningful input.

We created two sets of documents for these roles within the PAG; a Terms of Reference

and Role Description. These set out the duration, objectives and expectations of the role, a person specification, working methods, training and payment options.

The Terms of Reference and Role Description were agreed by all PAG Members before starting with the project, and we reviewed our objectives after the first year of working together to ensure they were still relevant. These documents templates have been co-developed by the University of Edinburgh's Usher Institute project staff and PPI contributors over time, through respiratory health data projects such as BREATHE.

We advertised for members using the People in Research website, choosing nine initial members to begin work in December 2020. The group was expanded to 15 people with another round of recruitment in August 2021. The original group represented a wide cross-

section of UK society. However, we wanted to include more people able to contribute to studies looking at the impact of the COVID-19 pandemic in terms of ethnic and socio-economic inequalities. We recruited additional contributors from ethnic minorities, socio-economically disadvantaged backgrounds, and more rural areas.

Both sets of members were given inductions to the project before attending PAG meetings. The inductions included an introduction to the project and its aims, an opportunity for members to introduce themselves, discussion

PAG membership

As the EAVE II project uses population data for the whole of Scotland and collaborates with similar projects across the UK, we aimed to include voices from a broad range of people. The PAG includes adult representation from Scotland, England and Wales; a wide range of ages; balanced gender representation; and people from a variety of health, physical and learning disability, socio-economic and ethnic backgrounds.

The group includes people who have had COVID-19 or care for those who have, as well as clinically extremely vulnerable people who were shielding. It also encompasses a variety of PPI experience, from people who are new to PPI to those who have been involved as project co-applicants or paper co-authors for a number of years. Members of the group also bring different skills and interests to the table, from linguistics to psychology and social care to computing.

To support the needs of individual projects, we also work closely with the Long Covid Scotland Action Group, and have collaborated with the Stillbirth and Neonatal Death Society (Sands) to provide sensitive messaging on pregnancy-related research.

of the terms of reference, and open questions. Working online during the pandemic meant that we were unable to recruit PAG members with no internet connectivity. However, we made provisions for the accessibility needs of individual members, including posting printed materials, providing accessible software and stationery, covering carer expenses and giving spoken descriptions of figures or graphs during meetings.

Although we were not able to include digitally excluded people in our research, the online format did allow for wider geographical representation and safety for clinically vulnerable members.



Working structure

The PAG have met approximately once every 4-6 weeks during the project. Originally the group was due to meet quarterly, but the pace of EAVE II's development required more frequent meetings to make PPI a meaningful part of the project.

All meetings were carried out on Zoom and chaired by the EAVE II PPI Coordinator. Minutes are recorded by one of our project administrators, and breakout sessions facilitated by the PPI Coordinator and Project Manager. The PAG started meeting for 60 minutes in the first instance, but requested to meet for 90 minutes starting in 2022 to create space for networking and further questions. Breakout sessions are used to ensure that each member of the group has time to speak, and can also get to know different members of the group better.



The structure of a typical PAG meeting.

In 2020-2022, the content of the meetings varied considerably depending on the needs of the PAG and research staff. Each meeting started with an introduction to the topic, typically followed by a PPI and project management update to discuss any developments in between meetings.

In the majority of sessions, we invited a researcher to give a short presentation to the group, who then stayed to get involved in subsequent discussion. Each meeting ended with a short Q&A session, which provided the opportunity to give feedback. Where available, documents and slides were shared in advance of the meeting. From 2022, each meeting was followed up with a one-page summary of the discussion at the request of the PAG.

The PAG have also been involved in a considerable amount of asynchronous contributions, carried out by email or virtual meeting depending on the needs of the individual. This includes contributions to analysis design, writing or reviewing summaries of publications in plain English, and shaping or reviewing grant applications, video content, animation scripts, and website utility.

We recognise our PPI contributors for their input in accordance with NIHR INVOLVE guidelines, being offered expenses and a payment of £25.00 – either as a voucher or a single annual bank transfer – for each hour of work carried out. This is one of the ways we ensure our contributors are valued for their time, effort and expertise. It also ensures that our contributors are not out of pocket, and that we do not exclude economically disadvantaged people from contributing to research.

Working together

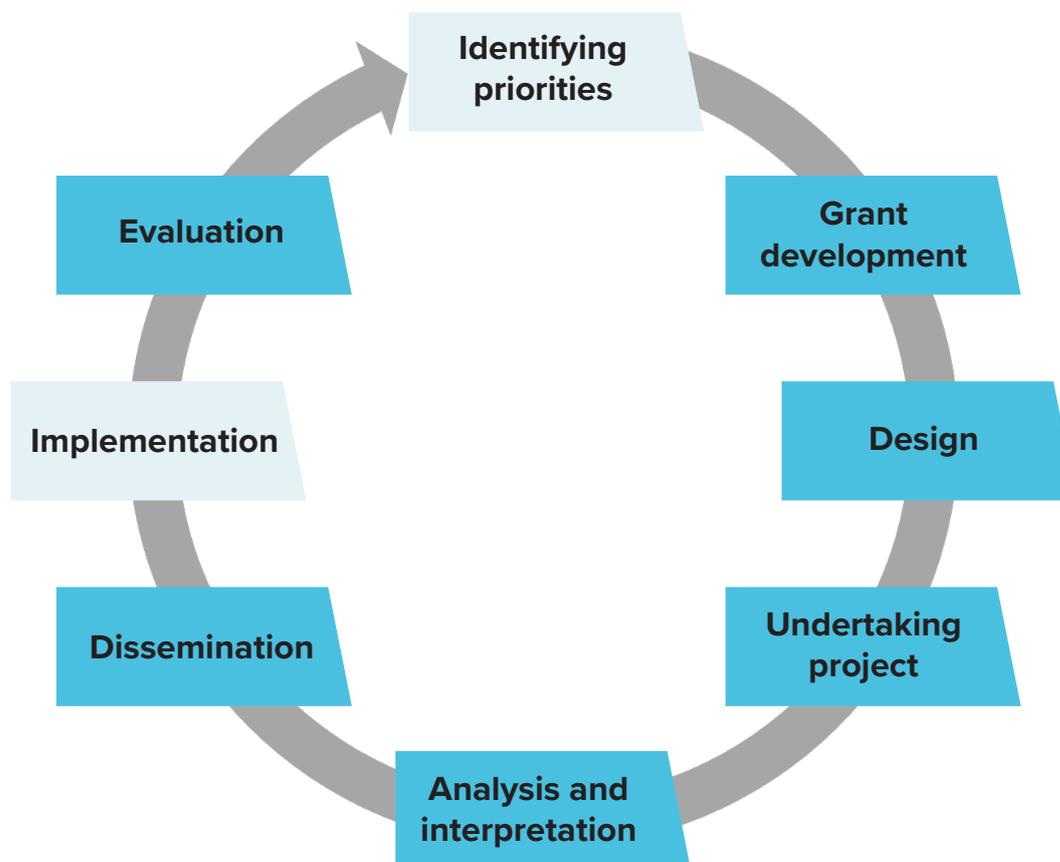
The PAG began work with a focus on our public-facing materials, including the website and research publication summaries. These activities come under Dissemination. As time has gone on, the Group have moved into all other relevant areas of the cycle.

The research questions answered within the first two years of EAVE II were necessarily set by the immediate needs of policy-makers during this global public health emergency.

This impacted the landscape of EAVE II PPI in two ways. Firstly, it reduced the agency of patient and public contributors in identifying research priorities. However, it greatly increased PPI contributors' real-life impact, in terms of shaping research that will directly shape policy. Examples of impact are

discussed on p12-13 of this report.

Aligning PPI with the research cycle allows contributors to actively shape research as it happens, throughout the project. Health data research can be thought of in terms of the following activities.



Patient and public involvement in the health data research cycle. The PAG started by focusing on how we disseminate EAVE II research, before moving into areas shown in blue.

Grant development

PAG members contributed to six grant applications between December 2020 and September 2021. This includes:

- acting as a lay co-applicant
- reviewing grant content
- shaping the project design
- writing or editing the project lay summary
- being involved in discussions that provided PPI evidence for continued project funding.

In initial contributions, PAG members felt that involvement could be improved and initiated earlier in the application process.

This feedback was incorporated, with the PPI content of two subsequent applications on COVID-19 vaccines and hospital readmissions being deemed 'Excellent' by funders (UK Research and Innovation, Health Data Research UK and the Alan Turing Institute).

Analysis design

PPI in health data research design can include looking at outcome measures and definitions, patient inclusion criteria, data quality, and how a particular tool might be configured for public use. The PAG have contributed to:

- discussions for current work on the impacts of ethnic and socio-economic inequalities on COVID-19, including data sources, data quality and intersections with disability;
- analysis protocols for our research on COVID-19 vaccines in children and young people, and new COVID-19 treatments;
- potential future work and messaging on the COVID-19 in Pregnancy in Scotland (COPS) project, including access to care, terminology and outcomes of interest;
- discussions about the use of public-facing apps to predict hospital readmission and Long Covid.

Undertaking the project

In health data research, PPI involvement in undertaking projects can include project steering, involving networks of contributors with relevant lived experience, and providing public perspectives throughout the research cycle.

To date we have been involved with 16 Steering Group meetings for the core project, as well as having dedicated PPI meetings and lay leads for specific studies (COVID-19 treatments, Long Covid).



We have also introduced a lay lead to sit on the Steering Group of the ethnic and social inequalities study, which is hosted virtually by the University of Manchester.

Sandra Jayacodi
 PAG Co-Lead
 and Steering
 Group Member



“Using population data means that, as with PPI, more people’s stories get included. That makes any decisions based on the research not only more accurate, but also fairer – whether that is for people from an ethnic minority, people living with suppressed immune systems, or people living in more deprived areas of the country.”

Where we felt that particular voices have been lacking, we have collaborated with contributors outside of the core PAG. This includes:

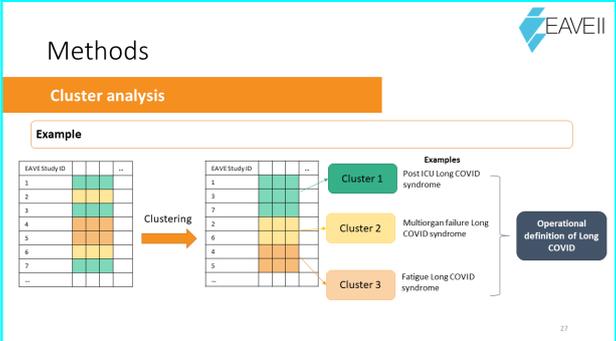
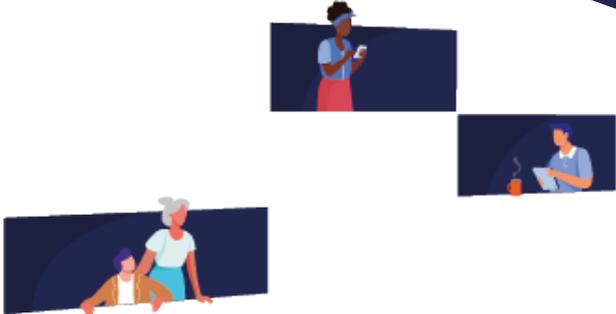
- **Long Covid voices:** Long Covid Scotland Action Group
- **Young voices:** 14-19 year olds, including Alumni from the University of Edinburgh’s Science Insights school programme
- **Voices on pregnancy:** Stillbirth and Neonatal Death Society (Sands) and research midwives.

Analysis interpretation

To date, the PAG have mostly been involved in interpretation through commentary on publication summaries. This is due to the speed with which COVID-19 related research has gone to press.

Their commentary has included questions about the use of chosen definitions or time periods, the inclusion of specific patient groups, and discussing the reasons why particular patterns of healthcare disruption or vaccine effectiveness may have emerged. In our Long Covid research, we have undertaken statistical methods training at the request of contributors, so that we can better interpret the results from a lived experience perspective.

This included descriptions of the four techniques used in the project: Natural Language Processing, Matched Analysis, Cluster Analysis, and Logistic Regression.



A slide explaining how Cluster Analysis is used to better understand patient groups.

Dissemination

To date, the PAG have reviewed 20 research publication summaries in plain English, and written another 6 themselves.

We have also reviewed infographic production, to ensure that the formatting used is as accessible as possible. The Group has also reviewed the EAVE II website, user-tested a web-based app for the linked QCOVID study conducted at the University of Oxford, and contributed to the script, content and filming for five videos and an animation.

In light of the volume of academic outputs emerging from the project, the PPI Coordinator produced a training guide for writing paper summaries in plain English. They have also supported several PAG members with one-to-one training and support in this area.

Our research on interactions between COVID-19 and asthma were accompanied by two Patient Perspective articles.



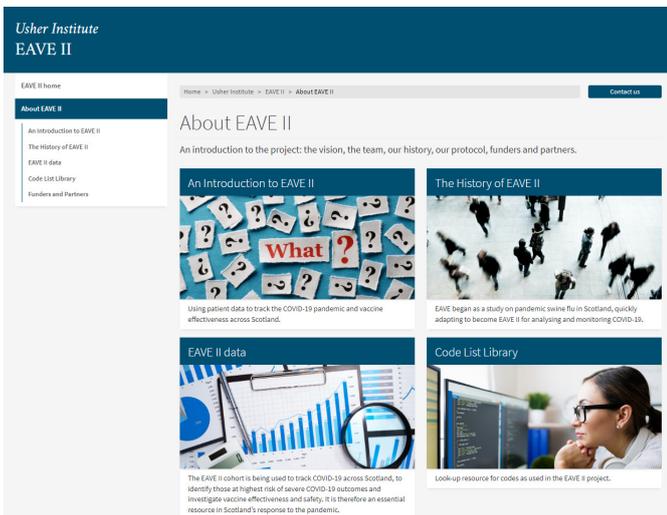
Kamil Sterniczuk
PAG Member

“As a member of EAVE II Patient Advisory Group I’m involved in improving COVID-19 research and publicising study results to the public. At the same time I’m learning new skills that allow me to make more meaningful contributions.”

These articles, produced by a PAG member and youth PPI contributor, commented on the research and were published in The Lancet Respiratory Medicine (DOI: 10.1016/S2213-2600(22)00013-3 and 10.1016/S2213-2600(22)00014-5).

In January 2022, one of our PAG Co-Leads spoke about PPI on the EAVE II project in a public webinar called “Health data: What’s in it for you?”, speaking to over 100 people about the benefits of health data and EAVE II results.

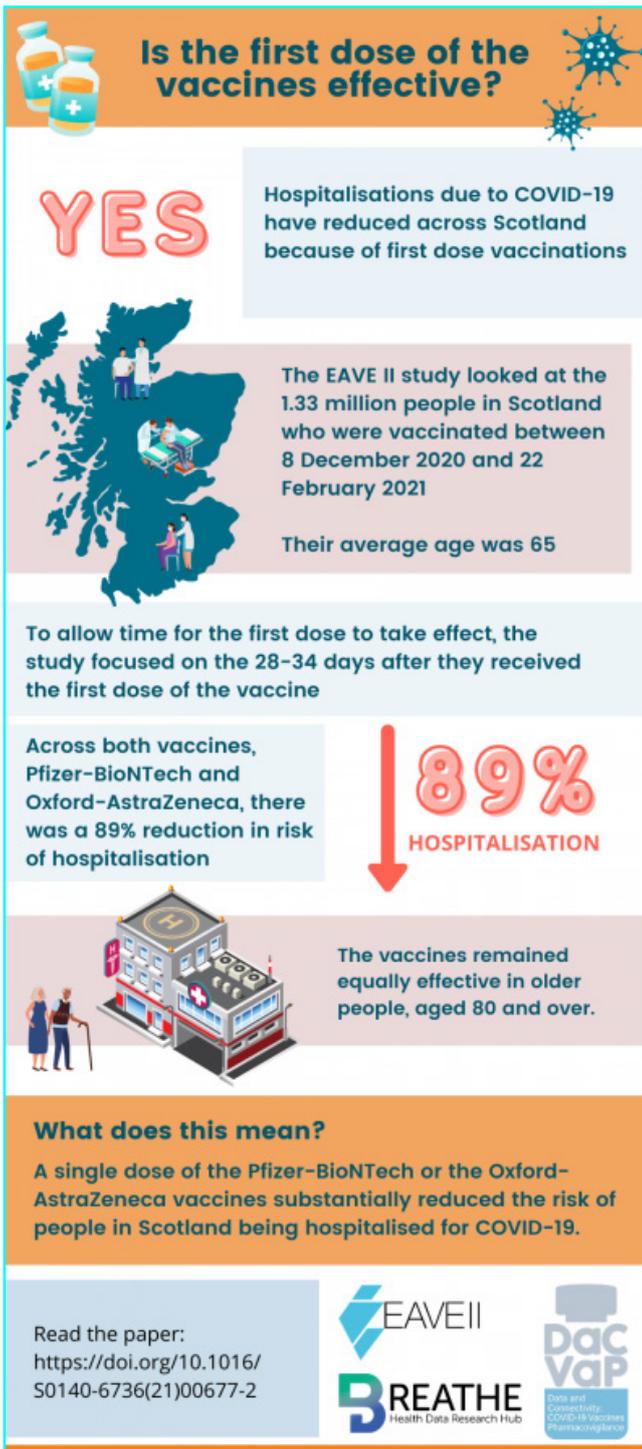
Expanding the readership of EAVE II’s public facing content has also been explored through a communication consultation with the PAG.



Information about the project on the University of Edinburgh website.

PAG member Sandra speaks alongside Aziz Sheikh and analyst Eleftheria Vasileiou at a public webinar run by the University of Edinburgh.





An example of a research infographic reviewed by the PAG for accessibility.

Evaluation

Evaluation of PPI can take many forms, including measuring the project and PAG role against their objectives; assessing PPI impact; and considering whether PPI input has been meaningful to contributors and staff.

In our Annual Review, PAG members felt happy with the objectives of their role as laid out in the original Terms of Reference and Role Description, and did not request any updates to these objectives.

All PPI activity on the EAVE II project is recorded using an Impact Log.

The PPI Coordinator records the context and date of the involvement, the people involved, points discussed, the impact or response, and suggested further actions from the PPI Coordinator, based on PAG requests or conversations with the wider team.

The PAG have committed to carrying out a more formal evaluation of PPI in EAVE II, including researcher perspectives, as a result of the Annual Review process.

Creating an impact

Tracking the impact of involvement on large scale projects can be challenging, as patient and public presence in itself can change the way that research is carried out and shared. Impact can also mean different things for public contributors and staff.

Nonetheless, the contributors and staff feel that PPI has had the following impacts on the project.

Grant applications and public benefit

Producing summaries of the grant application in plain English has enabled us to communicate project proposals from a public perspective. We have also discussed and shaped proposals alongside project staff.

Both the Long Covid and ISARIC HDR UK 4C-R proposals originally included risk prediction tools which would be made available to the public; allowing them to predict their own risk of Long Covid and hospital readmission respectively. This was assumed to be of public benefit in both cases. However, discussions of the two projects with the EAVE II PAG, and additional feedback from Long Covid Scotland members in the case of the Long Covid project, gave a consensus that this may not be the case.

Knowledge of personal risk may cause unnecessary anxiety for patients, particularly when learned in isolation and not part of a wider conversation with a trusted medical or care professional.

While it is good to be transparent about clinical staff using prediction tools, knowledge of risk is only useful to the patient in the context of clear care plans and patient agency – “what can I do as a result of knowing my own risk?”

Both publicly-available app proposals have now been removed from the projects. The 4C-R study has moved to consider risk prediction in the context of shared conversations between patients and their GPs.

Analysis design

As the PAG became an established part of EAVE II’s research cycle, we have had more opportunities to contribute to analysis designs. Two key projects where this has had an impact are the ‘Rapid Outcomes of COVID therapeutics in EAVE II’ (ROCOVE) project, and childhood COVID-19 vaccines analysis within core EAVE II work. Both consultations involved critiquing a summary of the analysis protocol, produced in plain English, and responding to guided questions.

The ROCOVE study aims to assess the safety, effectiveness and uptake of new COVID-19 treatments. New treatments include monoclonal antibodies and antiviral medication. Monoclonal antibody treatments mimic part of the body's immune response to COVID-19; antiviral treatments reduce the spread of virus in the body.

The team were expected to undertake extremely rapid analysis to provide data for key decision-making bodies across the UK.

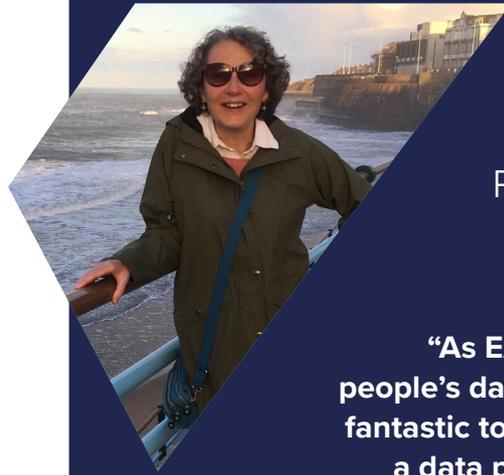
A number of changes to the ROCOVE analysis design have been made as a result of PAG input, and particularly the lived experience of people eligible for these new treatments.

This includes:

- describing safety and effectiveness in terms of interactions with existing medication;
- adding breathlessness, which was a key measure of recovery for potential patients;
- analysing the time between diagnosis and receiving treatment.

The PAG were also involved in the initial design for analysis of COVID-19 vaccines in children and young people (CYP), which forms part of the core research aim of EAVE II. They felt that:

- It is very important to consider protection against Long Covid as a vaccine effectiveness outcome for CYP;
- Hospital admission and death should ideally be reported separately for children, not as a single 'serious outcome' as with previous analysis in adults;
- It would be useful to compare vaccine side effect risks both to COVID-19 infection and to other common vaccines given to children, even if indirectly in the discussion;



**Lynn
Laidlaw**
PAG Member

“As EAVE II is using people’s data, it has been fantastic to be more than a data point and work in collaboration with the researchers to directly input into data analysis plans, and help share the findings in ways that are understandable and accessible.”

- There is general confusion around labelling of dosing regimens (partial/full vs first, second etc.), which should be made clear in any public-facing materials;
- Young people should be consulted about this project, to ensure it is relevant to their experience.

Some aspects of the PAG's input are currently limited by data availability, including Long Covid data and the ability to report serious COVID-19 outcomes in children separately, due to - thankfully - small numbers of cases.

On their request, we are currently exploring the results interpretation and dissemination from this project with people aged 14-19.

Data access, quality and limitations

The availability and quality of ethnicity data has been a key concern for PAG members in a Scottish health research context. As a result of lobbying by PAG members, the EAVE II team have gained access to a wider repository of ethnicity records which were not previously available to them. The quality of ethnicity data in Scotland is also being addressed in the long term by Public Health Scotland, and the Scottish Government have prioritised better recording of ethnicity data in healthcare settings to address the problems raised by EAVE II's Steering Group. We will continue to explore the validity of using other proxies, such as postcodes to measure socio-economic status.

In our February 2022 PAG Meeting, we discussed the patient journey in a COVID-19 context, and the factors which may be

included or excluded from routine data collection from a public perspective.

This discussion has directly contributed to a better understanding of how to build models that assess a patient's hospital readmission risk. It will continue to inform understandings of the limitations of EAVE II analysis.

Another key aspect of data access is transparency on data governance and linkage in Scotland. PAG members feel that although the EAVE II website and paper summaries provide clear information about our own use of data, explanations of general health data governance can be difficult to find in the public domain. This is particularly important in a Scottish context, where public, patient and research access to medical records differs to the rest of the UK.

Research in plain English

One of the key strengths of the EAVE II project is the number and quality of academic outputs, in addition to their timely release for key decision-making bodies. To make this body of knowledge accessible to a wider audience, the PAG have worked to ensure

that academic publications from the project, and analysis protocols where appropriate, are accompanied by a summary in plain English. We have worked rapidly as a team to make sure that these are available as soon as the research is published.

Sharing EAVE II's work in an accessible way

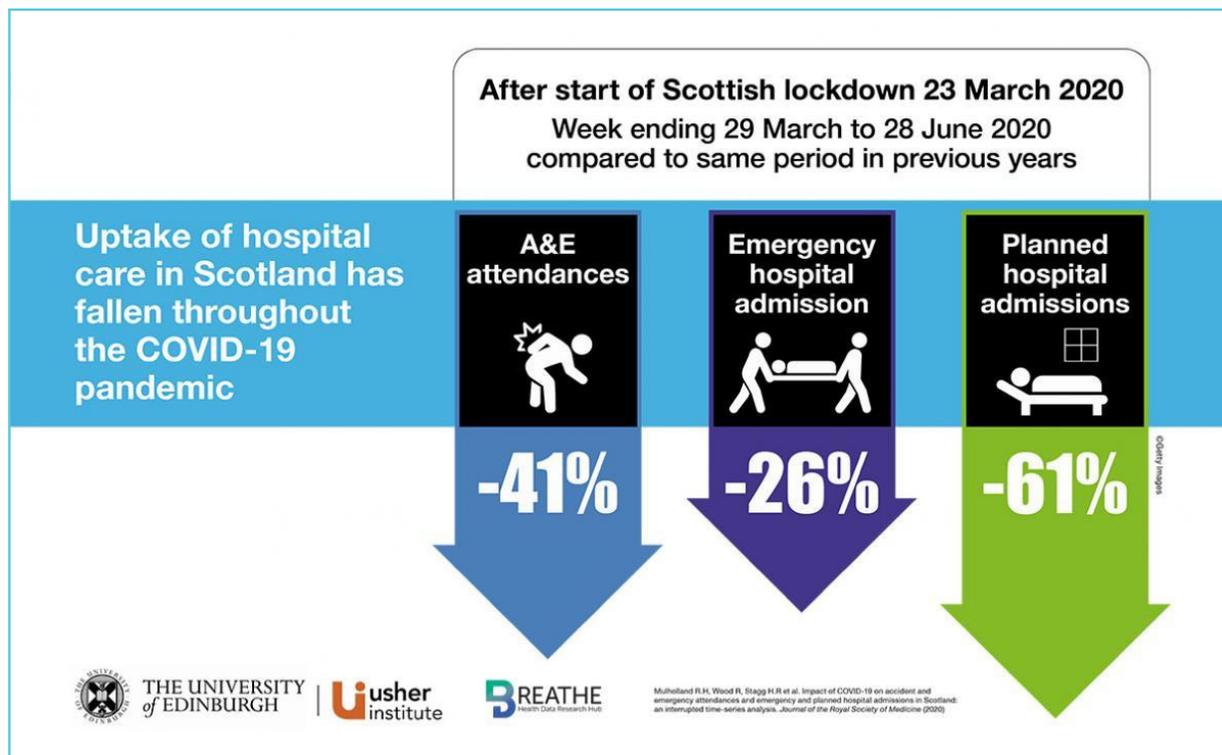
Many of EAVE II's academic outputs have been accompanied by an infographic summarising the research. In an early consultation about infographics, the PAG made changes to the font, colour and contrast choice, and use of alternative text to ensure that subsequent infographics were accessible.

Several audience members at the Research Insights talk about EAVE II, which included a dedicated PPI section, commented on how interesting it was to hear the patient perspective. In a consultation on the best way to share our work, the PAG felt that alternatives to text-based summaries would be beneficial, and more accessible for a general audience.

We discussed the possibility of hosting a public-facing COVID-19 research hub for Scotland, with a focus on communicating research for people with compromised immune systems.

Although the PAG felt that detailed, up-to-

date and public-friendly information about health data research was often difficult to find, we felt that this was beyond the remit of the PAG and agreed to contribute to central hubs as they emerge. This includes content on the Public Health Scotland and UK Covid Vaccine Research Hub websites.



An infographic about research on disruptions to hospital-based healthcare during the pandemic. The infographic shows key outcomes in understandable language, with high-contrast artwork which is accessible and memorable.

Contributing to other research projects

In addition to core EAVE II research, the EAVE II PAG has also helped to shape content for other COVID-19 related research projects:

Data and Connectivity: Vaccines

Pharmacovigilance (DaCVaP): This project monitored COVID-19 vaccines across the UK. We contributed to PPI looking at public perceptions of vaccines.

QCOVID 2/3: This project predicted risk of COVID-19 hospital admission and death. We user-tested the online prediction tool.

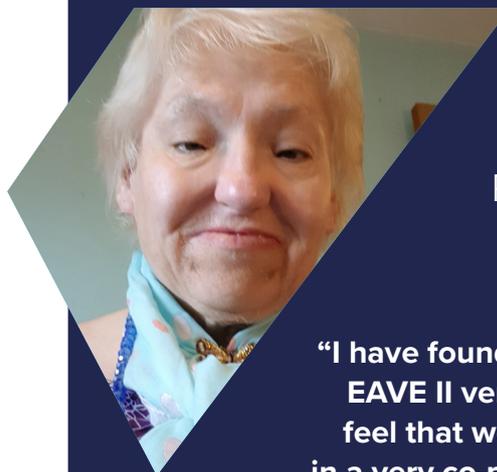
ISARIC HDR UK 4C-R: This project is creating a risk prediction tool for hospital readmission following a COVID-19 admission. We have contributed to the grant application, prediction tool public benefit discussions, and patient journey diagrams. We will continue to be involved with discussing AI model parameters.

Reflections and learning

PAG perspective

Previously, experienced PPI contributors have suggested that providing feedback via questionnaires after each 60-90 min meeting may be too much of a burden. In light of this view, we allotted space in the agenda for questions at the end of each PAG Meeting, and the PPI Coordinator highlighted openness to receive verbal or written feedback in meetings or via email.

At the end of the first year of active input, the original nine PAG members were invited to reflect on their experiences as contributors to the group throughout 2021. The team responded under the themes of Positives, Negatives, Improvements, Training and Terms of Reference, as well as general feedback.



Deb Smith
PAG Member

“I have found working with EAVE II very positive and feel that we have worked in a very co-productive way together, and hopefully made a difference.”

The PAG were also invited to shape and review the contents of this report, and the way it will be summarised for sharing with the public. Eight of these nine members responded and were recognised financially for their time.

Positives

- Organised, collegiate working and valued contribution to useful research
- Opportunity to learn about and discuss interesting work with enthusiastic researchers
- Variety of work and opportunity to actively contribute rather than just review

Negatives

- Impact is limited to existing PPI terms or individual projects
- Challenging to keep track of changes at pace
- Lack of face-to-face meetings and time constraints

Improvements

- Mechanism for making meetings less rushed; opportunity to catch up later
- More opportunities for more complex work; longer timescales
- Transparency around PAG and project governance; how everything works together

Training

- Getting involved in all areas of research, including identifying priorities
- Training for researchers on best-practice PPI
- Outline of project stages from initial concept through to conclusions

PPI Coordinator perspective

The EAVE II PAG has achieved an extraordinary amount in the past year, cheerfully keeping up with a complex project which is constantly evolving, but also being honest about what is practical and meaningful for them.

Their enthusiasm, responsiveness and passion for PPI has made them a delight to work with. EAVE II research, and the way it is communicated, has changed and improved as a result of their input. We have entered into dialogue not just about the research, but about what best practice PPI looks like for both experienced and new PPI contributors.

On this note, PPI mentoring and training has been identified as a focus for the future. Many of our PPI contributors would like to be involved with more complex work, regardless of their level of experience. This training applies to staff as well as PPI contributors, so that we can combine expertise to ‘tell the story behind the numbers’.

Analysis interpretation which is active, rather than retrospective, is another key area for PPI development in EAVE II. Meaningful public involvement could inform discussions of publication results in the drafting stage, including considering the driving factors in healthcare behaviour and disruptions.

Research team perspective

The EAVE II team work with the PAG in many different capacities, including in PAG and smaller PPI meetings, via the Steering Group, or indirectly through document reviews.

Many researchers who have worked directly with the PAG have commented on the usefulness of our PPI input, which provides perspectives they may never have considered for definitions, designs and outputs.

“PPI provides us with lived experience of conditions we research, and makes us look beyond the data. We have to ask more searching and relevant questions as a result of the PAG’s input.”

Dr Vicky Hammersley | Project Manager | EAVE II

“I have found the relationship with the PAG group to have been incredibly valuable as a data analyst. Sometimes my mindset is limited by the data dictionary and by what jumps out at me, so having that other perspective has been so valuable. We’ve made many changes to the [COVID-19 treatments] analysis plan, even for such a rapid project as ours was. There have also been many great ideas to take forward, continuing this work into the future. It has been a really invigorating experience.”

Dr Holly Tibble | Research Fellow | EAVE II

“It has been enriching and entirely valuable to work alongside the PAG – they advise us and hold us to account for the work we are doing, and how we communicate our findings. They are a credit to our success.”

Dr Josie Murray | Consultant Epidemiologist | EAVE II

Looking forward

The EAVE II project has shown that it is possible for PPI contributors, researchers and public health specialists to work alongside one another meaningfully on a fast-paced project, delivering evidence during a public health crisis.

We established successful patterns of involvement in grant development, analysis design and dissemination. The following areas have been identified for further work, on the basis of recurring themes and PAG suggestions throughout the project.

Data access and quality

‘Big health data’ is capable of providing incredibly powerful analyses, which can help to develop tailored public health strategies.

However, one of the key questions to emerge from our involvement with EAVE II is how we can support the use of external data sources which are as accurate as possible.

This is particularly the case for data related to ethnicity, socio-economic status, Body Mass Index, social support and poorly-coded chronic health conditions.

These questions are likely to form a part of our work going forwards, although the availability of the 2022 Scottish Census and data compiled by PHS will help with some issues. They are essential to understand vulnerable groups in future pandemics.

Potential PPI activities may include lobbying for better quality data, understanding how analysts account for missing or erroneous data in their work, and collaborating with qualitative researchers to understand factors not captured by routine data.

Supporting PPI contributors

Training and access are two areas that have been raised by PPI contributors as important for future work. This includes supporting PAG members to navigate University-based systems, mentoring less experienced contributors, and continuing to provide training on both project-specific methods and

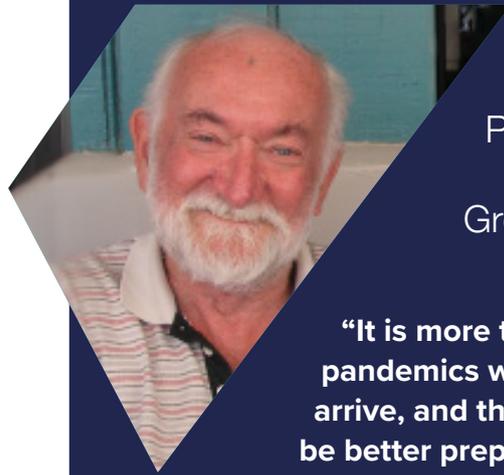
general research skills, such as writing papers, where the PAG members request this. We will continue to employ PPI structures with two co-leads to offer informal mentoring relationships between more and less experienced contributors.

Maintaining momentum on health data projects with embedded PPI

Maintaining positive long-term relationships with PPI contributors allows research projects to incorporate increasingly meaningful involvement, rather than addressing research dissemination alone.

By sustaining the EAVE II PAG, we will be able to consider public priorities for research using routine health data, which was not feasible at the start of the project. The group also offers a significant consultation resource for potential collaborators, and a well-established group for future pandemic research.

Continuing the PAG for future iterations of work will allow us to consider wider



David Weatherill
PAG Co-Lead
and Steering
Group Member

“It is more than clear that pandemics will continue to arrive, and the UK needs to be better prepared for these occurrences. I trust that EAVE II will form a part of that preparation through its continued development and maintenance. Many future health benefits will arise from its ongoing deployment as an invaluable rich research resource.”

challenges in a health data context, including transparency around data governance and the role of industry in research.

Acknowledgements

Heartfelt thanks go to all members of the Public Advisory Group – both public contributors and project staff who attend or support the group – for your input. We would also like to thank those who contributed to PPI from outside the EAVE II team. Thank you to David, Sandra, Ash, Carrol, Chris, Debs, Emily, Eve, Farzana, Hameed, JC, Joanna, Kamil, Laura B, Laura G-R, Lynn, Peter, Philip, Tamara, Tracy and Vicky. Particular thanks go to those PAG members who contributed to the Annual Reflection in December 2021, as well as shaping content for and reviewing this report.

Thank you also to the many staff in EAVE II who got involved with or championed PPI on the project, and to our funders who made this possible.



Glossary of data sources

The acronyms in the data source diagram on p5 are as follows.

COCIN

COVID-19 Clinical Information Network. Data on hospital admissions used to characterise severe COVID-19.

ECOSS

Electronic Communication of Surveillance in Scotland. Test results from diagnostic and reference laboratories.

HEPMA

Hospital Electronic Prescribing and Medicines Administration. Data on prescriptions distributed in hospitals.

NRS

National Records of Scotland.

OOH

Out of hours. Data on out-of-hours primary care consultations.

PIS

Prescribing Information System. Data on prescriptions distributed in the community.

RAPID

Rapid Preliminary Inpatient Data. Frequently updated information on hospital admissions.

SAS

Scottish Ambulance Service. Data on hospital admissions via ambulance.

SICSAG

Scottish Intensive Care Society Audit Group. Data on patients in general Intensive Care Units in Scotland.

SMR00

NHS outpatient data.

SMR01

Data for general or acute patient care in NHS settings.

SMR02

Data for maternity care/obstetrics in NHS settings.