University of East Anglia

Public Involvement Welcome Guide

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THE RESEARCH TEAM

Felix Naughton

Felix is a Professor of Health Psychology at University of East Anglia (UEA) and the **Principal Investigator** (PI) for this project. He is the overall lead for the eSupport programme.

Joanne Emery

Jo is a **researcher** at UEA and the eSupport **Programme Manager**. This means she will have day-to-day responsibility for the smooth running of the project.

Lisa McDaid

Lisa is a **researcher** at UEA and the qualitative research lead for the project. She is also **joint public involvement lead** with Carmen. **Lisa will be your main contact on the study team.**

Pippa Belderson

Pippa is a **researcher** at UEA working on the evidence review and qualitative research. She is also **helping to lead the public involvement.**

Esther Shackleton

Esther is a **researcher** at UEA helping with the qualitative research and co-development of the digital stop-smoking support package for pregnancy.

Gemma Richmond

Gemma is our eSupport **Programme Administrator**. She is very knowledgeable about all aspects of UEA and is a great person to contact with any practical questions.

THE WIDER TEAM

Carmen Glover

Carmen is a **member of the public** with an interest in stop smoking research and has been supporting research since 2017. She is **joint public involvement lead** with Lisa.

Our other public team members are: Carly, Roxanne, Debs, Laurel, Gemma, Eleanor and Zarah.

Caitlin Notley
Professor of Addiction Research, UEA

Zarnie Khadjesari
Implementation Scientist, UEA

Ruth Sanders
Midwifery Lecturer, UEA

Matthew Hammond
Clinical Trials Unit Interim Director, UEA

Allan Clarke
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Researcher, University of Nottingham

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Matthew Jones
Health Economist, University of Nottingham

Miranda Clark
Senior Clinical Trial Manager, University of Nottingham

Jo Leonardi-Bee
Professor of Medical Statistics, University of Nottingham

David Crane
and his team run the SmokeFree App

Elizabeth Bailey
Senior Lecturer, Birmingham City University

Sanjay Agrawal
National Specialty Adviser for Tobacco Dependency, NHS England

Michael Ussher
Professor of Behavioural Medicine, University of London & University of Stirling

WHAT IS THIS RESEARCH ABOUT?

We are developing and testing smartphone-based stop smoking support for people who are pregnant.

Smoking during pregnancy causes many **health problems for babies** before and after they are born. NHS pregnancy stop smoking support includes specialist counselling and Nicotine Replacement Therapy (NRT) delivered by a trained advisor. This support is effective, but not many pregnant people use it. Therefore, we need to explore different ways of delivering this support.

This project will create ‘eSupport’, a **digital stop-smoking support package for pregnancy**. This would include help to use NRT, and possibly vapes (if these become recommended in guidance). eSupport will be designed for use on its own and as an ‘add on’ to existing NHS pregnancy stop smoking support. The programme involves four workstreams (WS).

We will:

WS1**. Review** studies to find effective ways of helping people who smoke in pregnancy to quit by using digital support.

WS2. **Develop** the eSupport package by working together with people who have experience of smoking in pregnancy, experts on stopping smoking, and digital specialists. We will then offer this support to people who smoke in pregnancy and use their feedback to make it better.

WS3. **Test** the refined eSupport package in a randomised controlled trial to see if it helps people who smoke in pregnancy to quit, and whether it provides good value for the NHS.

WS4. **Promote** the eSupport package in different ways (via text messages, maternity notes apps or midwives) to learn the best way to maximise awareness and use.

WHAT IS PATIENT & PUBLIC INVOLVEMENT IN RESEARCH?

We need you because we believe you can help us do better research.

It is important that researchers listen to people who have experience of the topic being explored, so that they can make sure the research is relevant to them and is something that will make a positive difference. This ultimately leads to better services, treatments and care.

You do not need any research experience to be a public contributor - but if you do want to learn more about research, this is a great opportunity to do so!

The most important thing is you are enthusiastic about being involved in the study.

Remember - you will not be a participant in the research project but **supporting it as a public member of the team.**

> *"This type of research has been enlightening and beneficial to my own need to stop smoking and I have been able to use my smoking and vaping experience as bridges to aid each research study I have worked with."*

Carmen, eSupport PPI Co-Lead

Involvement:
Where members of the public are actively involved in influencing and shaping research projects by providing a 'public perspective' e.g.

- Member of a public advisory panel
- Commenting on and/or developing patient information leaflets and study materials
- Helping to make sense of research data
- Helping to share research findings

✓

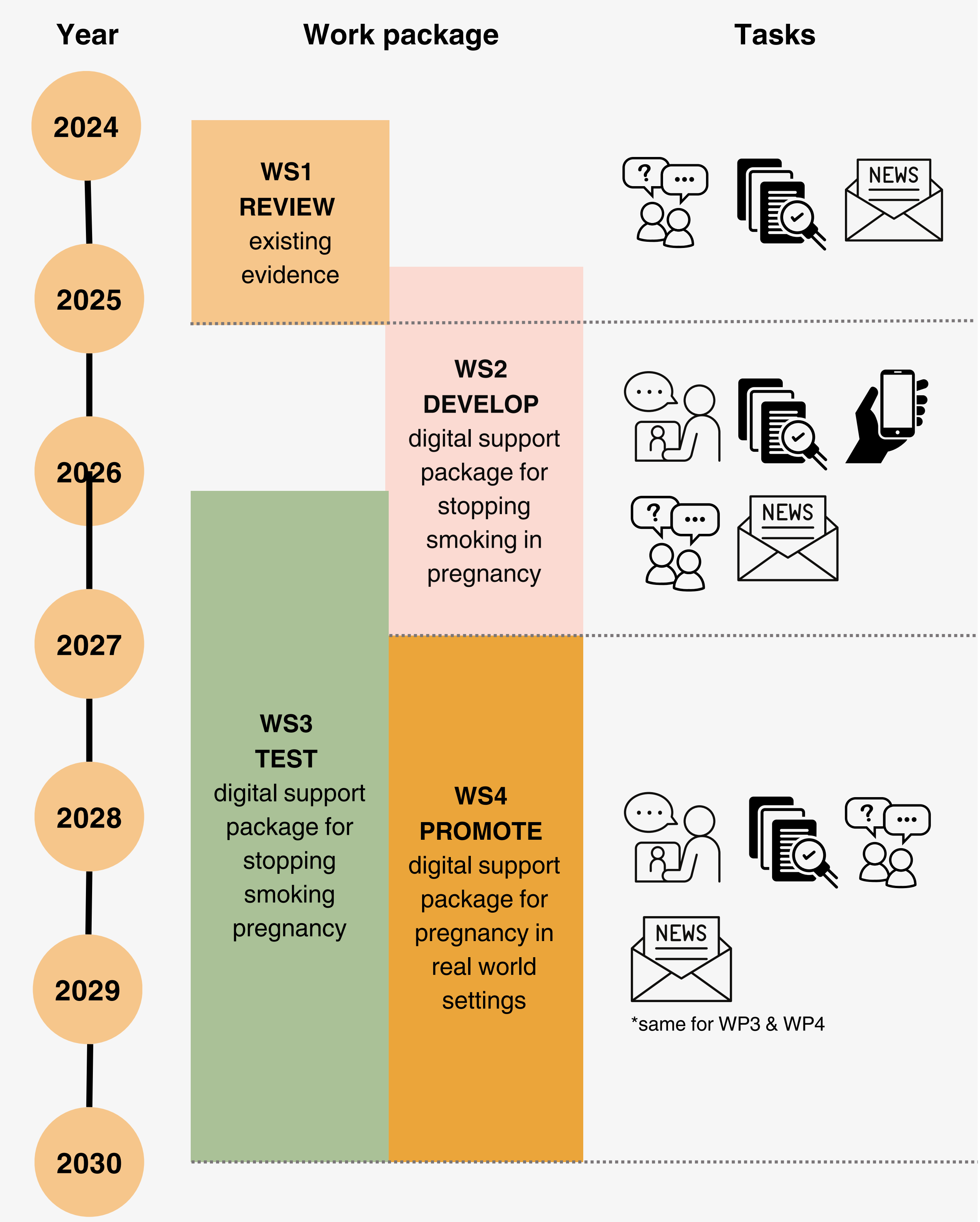
Participation:
Involvement is different from 'participation' where people take part in a research study e.g.

- People recruited to a clinical trial
- Completing a questionnaire or participating in a focus group

✗

WORKSTREAMS

There are lots of different opportunities to get involved with shaping the eSupport programme. How much you become involved and which tasks you help with is completely up to you.



Year

Work package

Tasks

2024
2025
2026
2027
2028
2029
2030

WS1
REVIEW
existing
evidence

WS2
DEVELOP
digital support
package for
stopping
smoking in
pregnancy

WS3
TEST
digital support
package for
stopping
smoking
pregnancy

WS4
PROMOTE
digital support
package for
pregnancy in
real world
settings

*same for WP3 & WP4

Public Advisory Panel and Programme Steering Group meetings will take place throughout.

TASKS YOU CAN HELP WITH

Attending Public Advisory Panel meetings

We will hold approximately **3-4 panel meetings a year** (online – although there may be opportunities for in-person meetings depending on how accessible this is for everyone). We may also ask you to attend specific meetings to help answer queries or issues that arise during the project.

1 Communication
2 Critical thinking
3 Problem-solving
4 Collaboration

Joining the Programme Steering Group (PSG)

The steering group provides oversight of the research study. Key activities involve monitoring the progress of the study, ensuring participant wellbeing is maintained, and providing advice to those delivering the study. There will ideally be **two public members** on the steering group. The steering group **meets at least once a year** (online meeting), though there may be periods when one or two extra meetings are needed.

1 Communication
2 Critical thinking
3 Problem-solving
4 Collaboration

Advising on practical aspects of the research methods

You may be asked to advise on aspects such as recruitment strategies, deciding on relevant outcomes, and ensuring participation is not overly burdensome. This will be done in meetings.

5 Creativity
2 Critical thinking
3 Problem-solving

Developing or reviewing documents

This is to make sure these are **easy to read, contain the necessary information or ask the right questions.** Some documents will be short, like the Participant Information Sheets or interview guides, but others may be longer, like the protocols (which describe how the research will be carried out) or ethics application.

- 1 Communication
- 2 Critical thinking
- 5 Creativity
- 6 Attention to detail
- 8 Jargon busting
- 10 Reading

Developing the digital support package

This might involve helping to **prioritise features, drafting content or testing how engaging it is** (i.e. is it practical, interesting, and easy to use). This will be done in workshops, meetings and app testing.

- 1 Communication
- 2 Critical thinking
- 3 Problem-solving
- 4 Collaboration
- 5 Creativity
- 7 Digital skills

Analysing and interpreting evidence

This might involve assisting in **developing themes** from interview or focus group data or seeing if you interpret this data differently to the research team. For the trial, this will include looking at the numerical outcome data to assess whether the support package has worked. This will usually be done in meetings.

- 1 Communication
- 2 Critical thinking
- 3 Problem-solving
- 9 Pattern recognition
- 11 Sense-making

Sharing findings with participants and public audiences

This may involve developing plain language findings summaries and social media posts, or designing visual aids such as infographics or videos. There may be the opportunity to help with webinars or public events, if this is something you enjoy.

- 1 Communication
- 5 Creativity
- 8 Jargon busting

FREQUENTLY ASKED QUESTIONS

How long will the research take?

This is a six year study, running between 2024-2030. You are free to be involved for all of this time, or just some of the time.

What will I get out of this?

It is an **opportunity to help other people** who want to quit smoking for pregnancy. It can i**ncrease your confidence, knowledge, and skills -** such as communicating ideas, listening respectfully to different views, problem solving and decision making - and **can be a great addition to your CV.** We also hope it is something **interesting and fun to do!**

How much of my time will it take?

We appreciate how busy life with small children or other commitments can be! How much you become involved and which tasks you help us with is completely up to you. The number and type of involvement opportunities available will change throughout the programme, meaning there will be busier and quieter periods.

What if I can't make every meeting?

That is ok. If you can make every meeting that is wonderful, but we recognise that you won't always be available. All we ask is that you help us when you can.

What if I am anxious about being involved?

Like many new things, we appreciate that becoming involved may feel daunting. We want you to feel as comfortable as possible about being part of the panel. We can offer a pre-meet and/or after meeting catch up for those who may find this helpful. If you don’t want to work in group situation, we can also work around this. Should you have any concerns along the way you are always welcome to contact Lisa or Pippa over email or to have a chat and we will do our best to help. You can also get in touch with one of our more experienced public members: Carmen or Debs.

Will I get paid for my time?

As a thank you for taking part, you will receive £20 per hour in shopping vouchers.

How will I receive my vouchers?

You will be emailed your voucher codes after each activity. We will ask you to reply to the email confirming that you have received your voucher code so we can keep this as a receipt for our records.

What if I do not want to be involved anymore?

That’s ok, your involvement is entirely voluntary. You can decide to stop being involved at all, or just to take a breather for a while and maybe rejoin later - all we ask is that you let us know.

Please contact us if you have a question and someone from our friendly team will get back to you.

JARGON BUSTER

Here is a list of some research terms you might hear us use and what they mean. If you are not sure about what something means, please ask a member of the research team.

Consultation	Consultation involves asking members of the public for their views about research, and then using those views to inform decision-making. This consultation can be about any aspect of the research process. Having a better understanding of people's views should lead to better decisions.
Citizens Academy	The centre that supports patient and public involvement activities at UEA.
CTU	Clinical Trials Unit, a department at a university (like UEA) which helps set up, manage and run trials for researchers.
Data	Data is the information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others, for example in reports, graphs or diagrams.
Dissemination	This involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through reports (often these are made available on the internet), publishing articles in journals or newsletters, writing media stories or sharing findings on social media, or speaking at conferences.
Ethics	Ethics are a set of principles that guide researchers who are carrying out research. Ethical principles are designed to protect the safety, dignity, rights and well-being of the people taking part. They include the requirement to ask everyone to give their informed consent to take part in a research project.
Evaluation	This involves assessing whether an intervention (for example a treatment, service, project, or programme) is achieving its aims. A project can be evaluated as it goes along or right at the end. An evaluation can measure how well the project is being carried out as well as its impact.

Focus group	A group discussion which is guided by a researcher to learn about options or experiences on a topic from study participants.
Implementation	Implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice.
Intervention	An intervention is something that aims to make a change and is tested through research. For example, giving a drug, providing a counselling service, improving the environment or giving people information and training are all described as interventions.
Interview	In research, an interview is a conversation between two or more people, where a researcher asks questions to obtain information from the participant(s) being interviewed. Interviews can be carried out in person (face-to-face) or over video or phone call.
Journal	A journal is a regular publication in which researchers formally report the results of their research to people who share a similar interest or experience. Each journal usually specialises in one particular topic area. The British Medical Journal (BMJ), British Journal of Social Work and The Lancet are examples of journals.
Methodology	The term methodology describes how research is done – so it will cover how information is collected and analysed as well as why a particular method has been chosen.
NIHR	The National Institute of Health and Care Research is the research arm of the NHS and the people who are funding this study.
Outcome Measures	Outcome measures are measurements of the effects of a treatment or service. They might include physical measurements – for example, measuring carbon monoxide in a person's breath to detect smoking, or psychological measurements – for example, measuring people's sense of well-being. If someone takes part in research, they may be asked questions, or they may be asked to have extra tests to assess how well the treatment or service has worked.
Participant	A participant is someone who takes part in a research study.

Patient Information Leaflet	Researchers must provide a patient information leaflet to everyone they invite to take part in a research study, to ensure people can make an informed decision about this. The leaflet explains what taking part will involve and how the results will be shared with others.
PPI/PPIE	Patient and Public Involvement and Engagement (PPI/PPIE) is an active partnership between patients and members of the public and researchers in the research process.
Randomised controlled trial (RCT)	This compares two groups of people (the experimental group who receive an intervention and a control group, who receive the usual care). The control group allows the researchers to see whether the intervention they are testing is any more or less effective than the usual care. In a RCT, the decision about which group a person joins is random (that is based on chance). This is important because it means that the researcher can be sure that any differences between the groups are only due to the intervention.
Research grant	Research grants are given to enable researchers to carry out a particular piece of research. Usually, in order to get research grants, researchers have to write a research proposal and receive a positive peer review.
Systematic review	Systematic reviews bring together the results of all studies addressing a particular research question to provide a comprehensive summary. For example, one clinical trial may not give a clear answer about the effectiveness of a treatment. This might be because the difference between the treatments being tested was very small, or because only a small number of people took part in the trial. So systematic reviews are used to bring the results of a number of similar trials together, to piece together and assess the quality of all of the evidence. Combining the results from a number of studies may give a clearer picture.
Workstreams	A study can be broken up into different stages, and this is a term we use to distinguish one stage from another.

Keep in touch

✉ esupport.study@uea.ac.uk

🌐 www.uea.ac.uk/groups-and-centres/addiction-research-group/esupport

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You can also contact the Citizens Academy if there is an issue with your voucher, for more information about patient and public involvement or to find out about other involvement opportunities.

Citizen Academy	citizens.academy@uea.ac.uk www.uea.ac.uk/about/faculties-and-schools/faculty-of-medicine-and-health-sciences/citizens-academy

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CITIZENS ACADEMY

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