

# UEA ADDICTION RESEARCH PUBLIC INVOLVEMENT PANEL

*Issue 1, Nov 2020*



Welcome to the first newsletter of the UEA Addiction Research Public Involvement Panel (UEA-ARPIP). For the last year we have been providing informal updates, but we thought it was time to get organised and find a regular way to keep everyone informed about the research carried out by the UEA Addiction Research Group (ARG) and other relevant news.

This has been a very different year for us all, and there has been no exception for research. This issue takes a look at the impact of the coronavirus on health research, and while it has created many challenges there are also opportunities to improve research moving forward.

The UEA Addictions Public Involvement Panel is still finding its feet, but after a recruitment drive at the beginning of the summer we are pleased to have 10 public contributors now involved. Our members have a range of experiences, strengths and skills and will be able to offer insights to ARG research that might otherwise be missed. We are now working with ARG researchers to identify involvement opportunities so that we can provide a matching service.

## Articles:

- The impact of COVID on ARG research
- Spotlight on ARG research studies
- Meet a UEA-ARPIP public contributor
- Meet an ARG researcher
- National public involvement update

This newsletter is produced by the University of East Anglia Addictions Research Group (ARG).

## Contact Us

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In this issue, we also take the opportunity to introduce some of the research carried out by ARG researchers, specifically studies focusing on smoking cessation and e-cigarette use, and introduce you to one of our ARG researchers and a member from our public involvement panel. Finally, we have included some national news on public involvement in research.

# The impact of COVID on research

The COVID-19 pandemic has brought about sudden change for health research. When social distancing measures were first introduced to reduce the spread of the virus many research studies were forced to temporarily pause or stop recruiting. Others had to develop new approaches to be delivered remotely; with face-to-face visits replaced by telephone and video calls, the use home-based testing, and participant samples, medicine and other treatments being sent by post. There has been much learning taking place, and while some of these changes might be temporary, others, such as having greater flexibility and making it easier for people to take part in research, might hopefully stick around.

Along with changes to research delivery, there has been a large redirection of funding towards research which focuses on COVID-19, and many research teams have shifted their focus to help understand what's going on with the virus. Researchers from the Addiction Research Group are currently leading on a study looking at changes in health behaviour and wellbeing as a result of the restrictions on daily living (C-19 Wellbeing Study). The findings will be used to inform the commissioning of health and wellbeing services and will contribute to policy planning in the future.

For many funders COVID-19 continues to be the number one priority, and we have seen a slowing in the number of new funding applications among ARG members – many of whom have been busy trying to get research activities which were paused back up and running. That said, there are lots of opportunities to explore the relationship between COVID-19 and addiction, and even though we face more uncertain months, it will soon be the right time to focus on new non-COVID studies as well.

Our public contributors involved with ongoing studies have needed to adapt to virtual working during this time and as researchers, we must continue to adopt approaches which are supportive and inclusive. However, with digital communication becoming the norm - we can also embrace the opportunity to work with public contributors from across the country.

It has been a quiet period for those people who have recently joined the panel. However, we recognise in these changing times, public involvement in research is more important than ever and we remain strongly committed to ensuring public involvement in all ARG research.

## ARG researchers

### **Professor Caitlin Notley (Lead)**

Research interests: tobacco smoking cessation, relapse prevention, electronic cigarette use, and substance dependency, misuse and addiction  
[c.notley@uea.ac.uk](mailto:c.notley@uea.ac.uk)

### **Dr Felix Naughton (Lead)**

Research interests: mobile phone interventions to support health behaviour change (mHealth), smoking cessation, electronic cigarette use  
[f.naughton@uea.ac.uk](mailto:f.naughton@uea.ac.uk)

### **Dr Pippa Belderson**

Research interests: food choices in older adults, nutrition in young people, abuse and neglect in young people  
[p.belderson@uea.ac.uk](mailto:p.belderson@uea.ac.uk)

### **Tracey Brown**

Research interests: lifestyle change to improve health, including: diet and food choices, diabetes, and smoking relapse prevention  
[tracey.j.brown@uea.ac.uk](mailto:tracey.j.brown@uea.ac.uk)

### **Dr Jo Emery**

Research interests: mental health interventions, smoking cessation, addiction, medication adherence, test development and validation, quantitative methods  
[joanne.emery@uea.ac.uk](mailto:joanne.emery@uea.ac.uk)

### **Dr Sarah Hanson**

Research interests: preventive health, including dietary and physical activity behaviour changes, cancer prevention and health inequalities  
[s.hanson@uea.ac.uk](mailto:s.hanson@uea.ac.uk)

## Spotlight on ARG research studies

# BABYBREATHE

This study will test a package of support, created by working with women, partners and NHS staff, to help women who have stopped smoking while pregnant to stay smoke free following the birth. The package is called 'BabyBreathe'.

Around ¼ of women in the UK report smoking in the 12 months prior to becoming pregnant. Over half of these women manage to quit while pregnant but at least half start smoking again after their babies are born. This can seriously affect the health of the mother and baby. Babies exposed to second-hand smoke have higher risks of cot death, breathing and ear problems.

The BabyBreathe package include support from a health visitor, a leaflet, a website, app, text message/notification support, and a BabyBreathe gift box to support staying smoke free after the birth of a baby.

We are very grateful to our two brilliant PPI contributors on the Trial Steering Committee for their support and insightful comments to help the study so far. We are also looking for two further PPI contributors for our separate Advisory group. If you are a new mum who has given up smoking in pregnancy, or know someone who is, please get in touch. This would involve attending 2-4 meetings a year and commenting on documents. We can reimburse our PPI contributors with shopping vouchers as a thank you for their time. If interested, please contact: [babybreathe@uea.ac.uk](mailto:babybreathe@uea.ac.uk)



## ARG researchers

### Professor Wendy Hardeman

Research interests: scalable behaviour change interventions, mobile health interventions, intervention fidelity, and process evaluation of complex interventions

[w.hardeman@uea.ac.uk](mailto:w.hardeman@uea.ac.uk)

### Dr Aimie Hope

Research interests: applying psychology to address environmental, technological and health related challenges

[a.hope@uea.ac.uk](mailto:a.hope@uea.ac.uk)

### Dr Zarnie Khadjesari

Research interests: digital alcohol support, online measures for drinking consumption, implementation of digital alcohol support in NHS settings

[z.khadjesari@uea.ac.uk](mailto:z.khadjesari@uea.ac.uk)

### Dr Lisa McDaid

Research interests: sexual health, smoking cessation, medication adherence, public involvement in research

[l.mcdaid@uea.ac.uk](mailto:l.mcdaid@uea.ac.uk)

### Dr Ian Pope

Research interest: admissions to A&E, smoking cessation in A&E setting

[i.pope@uea.ac.uk](mailto:i.pope@uea.ac.uk)

### Professor Fujian Song

Research interests: modelling for evaluation of health care interventions, research methods for evidence-based medicine, health services research, smoking cessation and tobacco control

[fujian.song@uea.ac.uk](mailto:fujian.song@uea.ac.uk)

### Dr Emma Ward

Research interests: e-cigarette use, smoking relapse prevention, new parents, young people and vulnerable groups

[Emma.ward@uea.ac.uk](mailto:Emma.ward@uea.ac.uk)

# Quit Sense

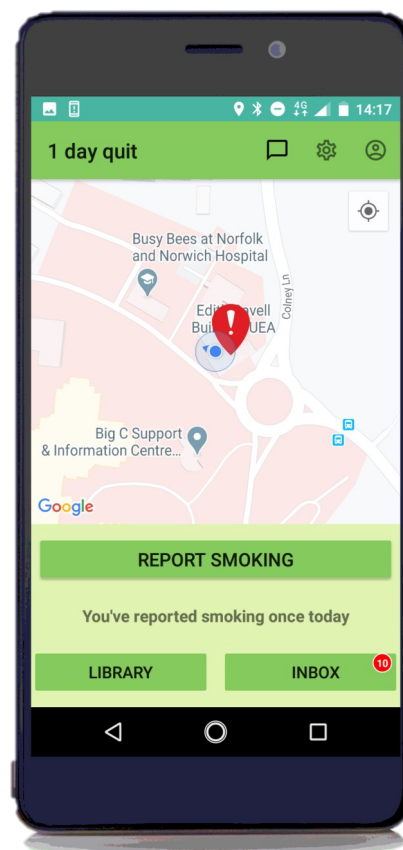
The idea for the Quit Sense app came from talking to smokers who were struggling to quit. They wanted help 'in the moment' to stop them reaching for a cigarette when they had an urge to smoke.

Quit Sense works by asking smokers, before they start trying to quit, for information about their surroundings (e.g. home, work) whenever they smoke and how they are feeling (e.g. down, stressed). Each time this happens the app uses the phone's in-built sensors (e.g. GPS) to record their location. Quit Sense sends them advice on how to avoid smoking whenever they approach or spend time in a place where they previously told it they had smoked. This is a new approach to help smokers and our pilot studies showed that Quit Sense delivers support as expected and participants like it.

This is a small feasibility study but, in the future, we want to run a large study to tell us if Quit Sense helps smokers to quit smoking. We will recruit 160 smokers using online adverts on the Google search engine and Facebook. Participants will have an equal chance of being put into one of two groups. There will be a 'usual care' group, who will be sent a weblink to the NHS' SmokeFree website which provides standard information about NHS help to stop smoking. There will also be an app group who will receive the same weblink but will also be given access to the Quit Sense app. Participants will be followed up at 6 weeks and 6 months after they start the study to collect information and to compare groups on smoking measures.

To find out more about Quit Sense, contact Aimie Hope: [a.hope@uea.ac.uk](mailto:a.hope@uea.ac.uk)

***“Quit Sense truly brings together people from different fields – psychologists and computer scientists have worked with members of the public to create what we believe is the world’s first context aware stop smoking app***





## Tracking via Repeated Assessment of Joint E-Cigarette and Tobacco use

Around half of UK e-cigarette users continue to smoke tobacco. While dual using both e-cigarettes and tobacco is common, it is not well understood. We want to understand more about people who both vape and smoke in order to make recommendations in terms of how to best support people who want to change their smoking behaviour, and inform policy-decisions on how e-cigarettes can be promoted effectively to help people stop smoking. The TRAJECT study aims to investigate patterns and trajectories of dual use behaviour and how this varies between individuals, and understand participant perspectives on their dual use behaviour.

This project is a partnership between UEA and London South Bank University. It is funded by Cancer Research UK. The study is led by Prof. Caitlin Notley and Dr Felix Naughton. Other team members include Dr Sharon Cox, Dr Allan Tyler, Prof. Lynne Dawkins, Dr Emma Beard, Dr Dominika Kwasnicka, Prof. Richard Holland. If you have any questions please feel free to contact Dr Emma Ward (Study Researcher) at [emma.ward@uea.ac.uk](mailto:emma.ward@uea.ac.uk)

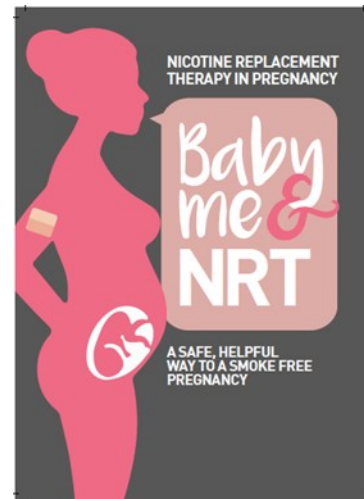
## N-READY



### Nicotine Replacement Effectiveness and Delivery in Pregnancy

The N-READY research programme aims to develop and test an intervention, called 'Baby, Me & NRT', that will support pregnant women to make better use of NRT to quit smoking. If it works, and increases pregnant women's NRT adherence, we will then carry out a further trial to establish the efficacy of the intervention for smoking cessation in pregnancy.

We have nearly finished the development stage, having tested and tweaked the support package by delivering it to three consecutive groups of women (40 participants). We appointed a Public Advisory Panel with four members who have past experience of smoking in pregnancy or an interest in the topic. They have helped ensure both the research and support package are acceptable and sensitive to the situations of our potential research participants. Their input to date has been so helpful, we only need to make very minor changes before we fully test the intervention next year!



If you have any questions, please contact Lisa McDaid  
[l.mcdaid@uea.ac.uk](mailto:l.mcdaid@uea.ac.uk)

## Meet the public contributor

Jo Hardy is currently a public contributor on the Quit Sense study. Jo studied Fine Art at the Norwich University of the Arts before spending over a decade as a martial arts instructor. Jo is an ex-smoker, who has also vaped.



### **How did you get involved with interested patient and public involvement?**

I got involved through a friend. She asked if myself and a few other ex-smokers would be interested giving some feedback on an upcoming research study, so I volunteered. The meeting went really well, and I found it interesting - and we were invited to be involved further with the research.

### **You are currently involved with the Quit Sense study, what has been your input so far?**

I've given feedback at all stages of the development of the app, such as wording, questions, design, layout and colour, plus the effects of Covid on the study.

### **How have you found being a public contributor on Quit Sense?**

I have found it really interesting. The team are friendly and keen to hear our feedback and ideas. An all-round positive experience.

### **What would you say to someone who is a bit unsure about getting involved in research as a public contributor?**

I personally enjoy contributing to something that could help many people improve their health dramatically and lives in general. It doesn't take up much time and I've been paid for my involvement which is a plus.

### **What else fills your time?**

I'm a mum of twins and run a pet care business. In my free time I enjoy running, cycling, photography, art and like to socialise.

***"I personally enjoy contributing to something that could help many people improve their health dramatically"***

## Training opportunities

The University of Oxford have developed further online training for public contributors as part of their ongoing series of webinars. The webinars are free, but you need to register in advance via the Eventbrite links.

**25<sup>th</sup> November, 2-3pm: Qualitative research**, presented by Dr Nikki Newhouse, Nuffield Dept of Primary Care Health Sciences <https://www.eventbrite.co.uk/e/patient-and-public-involvement-webinar-qualitative-research-tickets-126384101249?aff=ebdssbonlinesearch>

**3<sup>rd</sup> December 2-3pm: Finding and reading a research paper**, presented by Thomas Kabir, McPin Foundation <https://www.eventbrite.co.uk/e/patient-and-public-involvement-webinar-finding-reading-a-research-paper-tickets-126422608425?aff=ebdssbonlinesearch>

## Meet the researcher

Felix Naughton is a Senior Lecturer in Health Psychology within the School of Health Sciences at UEA.



### **When did you first come across PPI in research?**

At one of my first academic conferences there was a 'patient' attending, who was working with a research team. They gave a brief talk about their experience of being involved in the study they were supporting and what it was like living with the condition they had. For me it was one of the best talks of the whole conference and demonstrated how much more complete the study was with their involvement. It was then I realised how valuable PPI could be for research.

### **Could you explain more about the Quit Sense project?**

The idea behind Quit Sense came from participants in one of my first ever smoking studies. I was asking what they thought about receiving stop smoking advice by text messages and a few said that unless they were received around the point when they

were tempted to smoke, it wouldn't work very well. This got me thinking about how we might do this. Then a meeting with some computer scientists made me realise that, with their help, we could use location sensors in people's smartphones (GPS etc.) to work out where people were. Working with computer scientists, psychologists and stop smoking experts, we combined this location sensing approach with a smoking logging system (where people reported where they smoked and what triggered their smoking in that location), and this is basically the scaffolding for Quit Sense: An app that learns about a person's smoking behaviour and then sends support messages to help them avoid smoking in real time when they are in high risk locations.

Our latest study is a 'feasibility' trial which is in a sense a practice run for a larger trial and where we can start to estimate how the app might help smokers who are attempting to quit smoking. In the larger trial we will ask the questions *does it work* and *if so, how?*

### **How have public contributors been involved?**

We've had great PPI people involved in the Quit Sense

project. From the very beginning when we were designing and field testing the app, all the way through to now where we are doing the feasibility randomised controlled trial. All the key decisions, plans for how we will run a study, new features of the app, new messages in the app has had involvement from our PPI contributors.

### **What benefits and challenges has this brought to the project?**

Benefits include a whole range of things. From simple things like getting reassurance that we are not planning to do something which is unlikely to work or that people would not find acceptable, all the way to changing our research questions. For example, after talking with PPI contributors when we were planning to apply for funding for the feasibility trial, they highlighted how valuable it would be to have a bit more of a focus on estimating the impact of Quit Sense than we had planned, despite the relatively small sample size of the study. They also suggested we learnt more about which of our social media adverts were the most successful at recruiting people. Both of these things we are now doing.

I would say one of the biggest challenges is getting the right level of involvement in the project. Part of this is hitting the right balance for the individual PPI person and part of it I think is knowing what are the right questions for the researchers to be asking. Personally, I am still learning about how best to do this!

### **What is your ‘vision for the future’ of stop smoking research?**

We are at a really interesting time for stop smoking research. In terms of digital stop smoking support like

apps, there are some systems being developed looking at using machine learning to provide more personalised in the moment support, and we are also starting to look at other devices that might help people to quit.

For example, I am involved in a study based at the University of Bristol looking at smartwatches that use ‘gesture recognition’ to recognise the hand to mouth action of smoking, to better record and respond to smoking during a quit attempt. There are also lots of studies going on at the

moment exploring e-cigarettes and we will see many more like this answering key questions such as ‘what is the most effective behavioural support to help people quit smoking by using e-cigarettes’ ‘are there any long term health consequences from using e-cigarettes’ and ‘how can we best support people who want to stop using e-cigarettes’.

### **Anything else you would like to say?**

Simply two words to all PPI partners: ‘thank you!’

## **National news**

### **UK Standards for Public Involvement**

A new handbook has been published sharing the stories of organisations that tested and used the UK Standards for Public Involvement in their research as part of a pilot programme.

Last year a set of UK standards for Public Involvement in research was launched, which aimed to help researchers and organisations improve the quality and consistency of public involvement in health and social care research. The standards were subject to a public consultation and piloting phase involving a network of over 400 registered individuals. In

addition, the standards were tested in a year-long programme.

As part of this pilot programme, 10 projects were chosen to test the draft standards during 2018–2019, providing feedback and suggestions. The selected projects spanned organisations, regions and research settings and varied in their size, experience of public involvement and research focus. Now, a new handbook has been launched sharing the experiences of these projects in implementing the standards. The stories are designed to give a glimpse of the different ways the standards were used and integrated into ‘business as usual’ research,

or  
as



part of special projects. The National Institute for Health Research (NIHR) hopes the booklet will inspire researchers and members of the public to consider how the standards could be applied in their research or research involvement. For more information, see <https://sites.google.com/nihr.ac.uk/pi-standards/>