

Help BEAT Kidney Disease: New campaign launching Spring 2018

We're delighted to welcome a fourth 'Help BEAT' campaign to Research for the Future. Help BEAT Kidney Disease will officially launch on World Kidney Day on 8 March, an annual day that highlights the importance of good kidney health.

The kidneys carry out many important functions in the body. They remove excess water and waste, regulate blood pressure, make red blood cells and help keep your bones healthy.

Chronic kidney disease (CKD) is a common long term condition where the kidneys don't work as they should. It is often associated with getting older or caused as a result of other conditions including diabetes, high blood pressure or nephritis (inflammation due to infections or autoimmune conditions).

Approximately 8% of the UK adult population have CKD, with black, Asian and other minority ethnic communities at highest risk of developing the condition. In Greater Manchester there are more than a thousand adults currently receiving kidney dialysis.

Philip Kalra, Professor of Nephrology, University of Manchester and Salford Royal NHS Foundation Trust welcomed the launch saying,

"I am delighted that Help BEAT Kidney Disease campaign has joined Research for the Future in Greater Manchester. Early kidney disease is common, and many people are at risk of developing serious complications including the need for dialysis or a transplantation, which can have significant effects upon their lives. This campaign will enable



people to sign up to be informed about research that they might participate in, so that together, we can help to improve the lives of people with kidney conditions."

If you have kidney disease and would like to hear about kidney research opportunities please contact the office.

Research for the Future win 'best website'

We were delighted to win 'best website' in the NIHR 'Let's Get Digital' awards. The competition recognises the ways in which people can 'get digital' and raise awareness about research.

Research for the Future was one of five entries shortlisted in the website category, which were reviewed by an expert judging panel and put to a public vote. Judges said that the website is clear with colourful content, describing it as vibrant and well-designed from a user experience perspective.

Together with the other winners, the team visited the Google headquarters in London, where they gave a short presentation about their winning entry and heard about the future of digital.

We would like to thank everyone who worked with us to develop the website and who took the time to vote. Special thanks go to our wonderful volunteers who, through their participation in health research, are helping discover the best ways to prevent, diagnose and manage long term conditions.



Do you use email?

More than three quarters of our volunteers use email, meaning they find out about new research opportunities as soon as they are available.

Choosing to receive information by email also means that printing and postage costs are reduced. If you have received this newsletter by post but use email please let us know.



Help BEAT
Diabetes



Help BEAT
Heart Disease

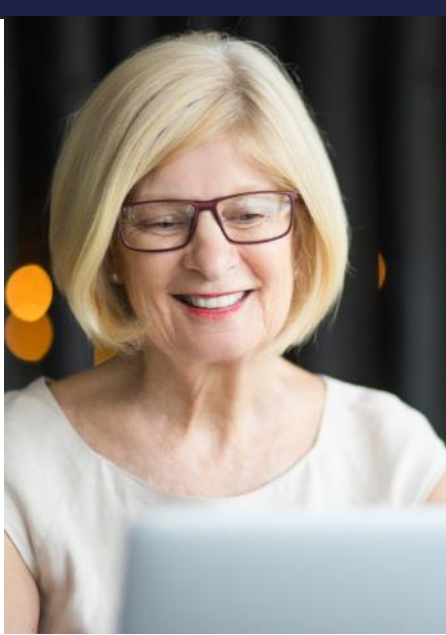


Help BEAT
Kidney Disease



Help BEAT
Respiratory Disease

Encouraging people to get involved in research
www.researchforthefuture.org



Diabetes study gets results: Thanks to Help BEAT Diabetes volunteers

Researchers at the University of Liverpool were thrilled by the response when they asked Research for the Future to help find 100 people with diabetes to take part in a study looking at anxiety and depression.

A staggering 400 of our volunteers responded to the invitation to take part, making up a large proportion of the 614 people who participated in the study.

Volunteers were asked to complete two online questionnaires over a three month period. The questionnaire wanted to find out how people with diabetes understand the nature of depression. The results of

the study showed that metacognitive beliefs (what we believe about our own thinking and how we interpret our thoughts) are associated with anxiety and depression in people with diabetes, especially those with type 1.

Dr Peter Fisher (Senior Lecturer in Clinical Psychology, University of Liverpool) thanked volunteers for their participation saying, "you turned our project into a success".

The results of the study, including a thank you to Research for the Future, have now been published in the journal Diabetes Research and Clinical Practice.

Are you a patient research ambassador?

A patient research ambassador (PRA) is someone who promotes health research from a patient point of view to other patients, the public and healthcare professionals. A PRA helps make sure that people using local NHS services have the best opportunities to take part in research studies.

The National Institute for Health Research (NIHR) in Greater Manchester is looking for people who would like to be a PRA, helping make sure patient voices are included in all their research. Being a PRA means you will also receive news about training and learning opportunities, events and meet ups with other PRAs in your area. To find out more about being involved please contact Janet Eastwood on **0161 276 4646** or email janet.eastwood@mft.nhs.uk

Singing helps your breathing

Do you know that singing can have a positive impact on people living with a lung condition? Our charity partner, The British Lung Foundation (BLF) have developed a new 'singing for lung health' training programme in consultation with a leading music therapist.



The programme aims to improve the physical and psychological well-being of people living with chronic lung conditions by training singing instructors and supporting them to set up local BLF singing groups.

Katie Merrick, Service Development Manager at the BLF explained, "*there is increasing evidence that singing helps people living with lung conditions such as COPD to improve their quality of life*"

The BLF are currently recruiting singing instructors in the North West, including Salford, Manchester, Tameside and Glossop. For more information on how to become a BLF singing leader or to register interest in joining a group, please email singing@blf.org.uk. For more information about BLF singing groups, please visit their website: www.blf.org.uk

Do you have asthma? Can you help?

A new study is looking for people with asthma to try out a home monitoring system to see if this could predict asthma control and help people manage their condition better.

Taking part would involve attending one clinic appointment at Wythenshawe hospital and using the home monitoring system for a year. Participants must continue to attend their normal respiratory appointments and take their prescribed medications.

To take part you must have attended A&E for your asthma in the past year or needed a course of steroids for at least three days. You will need to have regular access to WiFi. For further information please contact the office.



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Research for the Future

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Salford Royal NHS Foundation Trust, Stott Lane, Salford. M6 8HD

Research for the Future encourages people to take part in NHS health research in Greater Manchester. Our 'Help BEAT' campaigns invite people living with certain health conditions to find out about research opportunities relevant to them. Our current campaigns include; **Help BEAT Diabetes**, **Help BEAT Heart Disease**, **Help BEAT Kidney Disease** and **Help BEAT Respiratory Disease**.

The project is provided in partnership with the National Institute for Health Research (NIHR) Clinical Research Network Greater Manchester, Salford Royal NHS Foundation Trust, North West EHealth, and Health Innovation Manchester.

Charity partner for 'Help BEAT Heart Disease' campaign

The Pumping Marvellous Foundation is the UK's patient-led, heart failure charity supporting patients, families and carers to manage the condition. Their aim is to inform, raise awareness, offer patient-to-patient support and patient-authored resources for people living with heart failure – a condition affecting around 900,000 people in the UK. We're delighted they are supporting our Help BEAT Heart Disease campaign and are really looking forward to working with them.

Nick Hartshorne-Evans, Founder and Chief Executive Officer said,

"As the UK's leading patient led heart failure charity, we are delighted to partner with the National Institute for Health Research in Greater Manchester as part of their 'Help BEAT Heart Disease campaign'. Together we can continue to help heart failure patients live their lives as well as they can."



Join us on Facebook

In our last newsletter we shared the findings of our social media survey that highlighted many of our research volunteers prefer to use Facebook over the other social media sites such as Twitter or Instagram. Over the last few months we have invested a lot of time in our Facebook page, and have used it to share important self-care advice and information from our charity partners; Diabetes UK, Pumping Marvellous and British Lung Foundation.

We now have more than 600 followers and are looking at ways we can use Facebook, in particular to support our doctors, nurses and other research staff. Over the coming months, we will increase our online profile to promote studies and research opportunities that might be suitable for you to get involved in. If you're online please come and ['like' us!](#)

Research participation

Thank you to all Research for the Future volunteers who over the last year have helped to improve care and treatments for future generations.

More people took part in clinical trials in Greater Manchester last year than ever before, including:

- 2738 in heart disease studies
- 1566 in diabetes studies, and
- 649 in respiratory studies.

It wasn't just clinical trials that people were involved in though and many more volunteers participated in patient panels, discussions and completing questionnaires. Every participation, no matter how small, makes a difference.

Out and about:

Over the past few months we've been working closely with our charity partners to promote and help the valuable work they do.

Diabetes UK are currently working with NHS organisations across Greater Manchester to gather the views of people living with diabetes to help improve care and shape future services. We've made sure our Help BEAT Diabetes volunteers have been kept informed about the consultation events, so they can contribute and have their voices heard, as well as attending a number of the events ourselves.

The British Lung Foundation invited us to attend a number of their friendly Breathe Easy support groups across the region, where we've had chance to try out some singing exercises for lung health! We also had a stall at the NIHR Greater Manchester research fair and film screening of 'People are Messy', designed to encourage discussion about taking part in research.



Help BEAT
Diabetes



Help BEAT
Heart Disease



Help BEAT
Respiratory Disease

Encouraging people to get involved in research
www.researchforthefuture.org

Spotlight on research: Clinical trials

When people think of research they often think of a scientist wearing a white lab coat. Whilst this may be true in some cases there are lots of other ways that the NHS carries out research. In each newsletter we shine the spotlight on one of these areas, explaining how it works and giving some examples of how our volunteers have contributed. This time the spotlight is on **clinical trials**.

Clinical trials are research studies which compare a new or different type of treatment with the best treatment currently available. They are carried out because we don't know whether the new treatment is better than the current treatment or not. The new treatment being proposed could be a drug (eg tablet

or medicine), medical equipment (eg inhaler or glucose monitor) or a lifestyle change (eg diet or activity).

Clinical trials aim to find out which treatment works best, is the safest and has the fewest side effects. They usually involve dividing people into two or more groups; one receives the new treatment and the other the current treatment. Researchers follow a strict protocol which is like an operating manual. It makes sure every researcher performs the study in exactly the same way so that the study produces the best possible results.

Results from a clinical trial could find out the new treatment is better than what is currently available; is no different or is not as effective. Results help the NHS continually



improve treatments and make decisions about the best ways to prevent, diagnose and treat illnesses.

For some people who are not responding to the usual treatments, clinical trials can be a way to receive promising new treatments.

How you are helping with clinical trials

Some of our Help BEAT Diabetes and Help BEAT Heart Disease volunteers are currently taking part in a clinical trial called **HOMAGE** (Heart OMics in AGEing) which is taking place at a number of research centres across Europe including the Manchester Heart Centre at Manchester Royal Infirmary.

HOMAGE is looking at whether specialised blood tests can help identify the risk of developing heart problems and if a medication can reduce that risk. Taking part in the trial involves attending six clinic visits over nine months. Participants have a number of investigations including clinical examination, electro-cardiogram (ECG), blood and urine samples and a walking test.

Fozia Ahmed, Consultant Cardiologist at Manchester Royal Infirmary is delighted with the number of 'Help BEAT' volunteers who have joined the study and explains there is still time to get involved, *"...recruitment for HOMAGE is still open. If you are thinking about taking part or have any questions*

before making a decision, our research nurses can discuss this with you."

To take part you must be over 65 with no heart failure. You also need to have had previous heart surgery/stent OR have diabetes and high blood pressure and taking medication for both. Please contact Research for the Future for further details.



HOMAGE

Can you help ?

**Do you have type 2 diabetes?
Do you have relatives in the
Liverpool area who don't?**

Researchers at Aintree University Hospital in Liverpool are looking at physical activity in people who have a family history of type 2 diabetes but do not have the condition themselves.

Taking part in the study would involve your relative attending some clinic appointments at the hospital.

If you have a parent, brother, sister or child aged 18-60 years old who may be interested please ask them to email Kelly at k.bowden-davies@liverpool.ac.uk or telephone **0151 529 5940**.

 **0161 206 3636**

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Research for the Future

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Research for the Future encourages people to take part in NHS health research in Greater Manchester. Our 'Help BEAT' campaigns invite people living with certain health conditions to find out about research opportunities relevant to them. Our current campaigns include; **Help BEAT Diabetes, Help BEAT Respiratory Disease and Help BEAT Heart Disease**.

The project is provided in partnership with the National Institute for Health Research (NIHR) Clinical Research Network Greater Manchester, Salford Royal NHS Foundation Trust, North West EHealth, and the Greater Manchester Academic Health Science Network (AHSN).



January 2017

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Research for the Future and the 'Help BEAT' campaigns

Research for the Future encourages people in the Greater Manchester area to get involved in health research through their 'Help BEAT' campaigns (Diabetes, Heart Disease and Respiratory Disease). Joining our campaign means we'll let you know how to get involved in local NHS research going on into the condition(s) you have. If you live elsewhere in England you are still very welcome to join, but there will be fewer opportunities to take part in research through us.

British Lung Foundation (BLF) supports Help BEAT Respiratory Disease

We're delighted the British Lung Foundation is now a partner in our Help BEAT Respiratory Disease campaign and look forward to working together. Katie Merrick, Service Development Manager, BLF explained, *"We are pleased to be partnering with the NIHR as part of their 'Help BEAT Respiratory Disease' campaign. This will enable more people across Greater Manchester affected by respiratory conditions to sign up for research to help improve lung conditions, receive BLF support and find out about the level of care they should be receiving."*



Your award winning team

In October, the Help BEAT Diabetes campaign was highly commended at the prestigious 2016 Quality in Care awards. These awards recognise and share good clinical practice. The award was presented to the team by Simon O'Neill, Director of Health Intelligence and Professional Liaison at Diabetes UK.



The judges feedback was, *"connecting patients to research is great for diabetes... and the take-up rate so far has been pretty amazing!"*

In November, Research for the Future won a further two awards from the NIHR Clinical Research Network in Greater Manchester. The first for the team's public engagement across the region and the second an outstanding contribution award for our advisor Lillian Fallows. Many of you will know Lillian as she sends you information about local research studies. We're thrilled her enthusiasm and hard work has been recognised. The judges commented, *"Every team needs a Lillian"*. We couldn't agree more!



Internet and social media survey

Thanks to everyone who took part in our recent social media survey. We discovered whilst many of you regularly use the internet, you haven't yet visited our website www.researchforthefuture.org Don't miss out! Our website has information which many of you said would be helpful such as the types of research we offer, studies currently recruiting and updates on studies you may have been involved in. Similarly, lots of you use social media (e.g. Facebook, Twitter) but haven't yet connected with us. If you 'like' us on Facebook and 'follow' us on Twitter you can see what we're up to! Results from this survey will help us plan a social media campaign in the near future.



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Find us on Facebook:
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Out and about We promote the 'Help BEAT' campaigns across Greater Manchester as much as we can. During summer we joined Diabetes UK at their roadshows in Blackburn, Accrington, Middleton and Oldham. We had fun at Wythenshawe Games in July and in later months were invited to be part of NHS Trust open days in Bolton, Tameside and Central Manchester. A very memorable event was joining Salford's research teams at a festive pop up shop in December and making some Research for the Future baubles to decorate the Christmas tree. Come and say hello if you see us out and about, we love meeting everyone! If you are organising an event and would like Research for the Future to join you please get in touch.



Spotlight on 'types of research'

When we ask people what they think research involves, the answer we often get is someone who wears a white coat and works in a laboratory! Whilst this may be true some of the time there are lots of other ways researchers carry out their work. In each newsletter we explain more about the types of research we offer and give an example of how you have helped. This time the spotlight is on **observational studies**.

Put simply, observational studies mean the researcher is 'observing' an aspect of your health results. This usually involves having some tests, e.g. a blood sample or scan.

You may also be asked some questions about your health. Observational studies never involve testing any medical equipment, tablets or medicines.

Researchers look at results from large numbers of people in observational studies to see if there are any links between your health condition and things such as family history, blood or other test results. Results from observational studies help researchers understand more about a condition and the best ways to manage it in the 'real world'.



How you can help with observational studies

Since 2015, over 200 of our Help BEAT Diabetes volunteers have taken part in an observational study called DARE. People with diabetes are asked to donate a sample of blood, have their height and weight recorded and answer a short health questionnaire. Results will help researchers understand diabetes genes and why some people are more likely to get this condition.

Taking part in this study only takes about an hour of your time so if you have never taken part in a research study before this is a great way to start. Sam, one of our diabetes volunteers, told us *"taking part in DARE was my first research study. It was a positive experience and one that I would be happy to repeat"*. You can read more about Sam's experience taking part in DARE by visiting the diabetes case study section of our website at <https://www.researchforthefuture.org/cs-research-area/diabetes/>

Thank you to Sam and everyone else who has already taken part in DARE. If you haven't yet, and would like to, please contact us to find out your nearest participating hospital (Greater Manchester only).



Recruiting in record time

Earlier this year we were contacted by the University of Oxford, asking if we could help them find 100 people to participate in a blood pressure questionnaire. They were amazed when over 200 of our 'Help BEAT' volunteers completed the survey in just 48 hours! Researcher Ben Fletcher explained the impact this will have, *"having so many responses gave us really interesting results. Thanks to 'Help BEAT' volunteers we can publish our findings sooner"*.

Have your details changed?

Recently changed your email address, mobile number or moved house? Please remember to let us know if your contact details change. If you want to check the details we hold for you are correct please get in touch.



We wish you a happy and healthy New Year!

You are receiving this newsletter as you agreed to receive information about health research through Research for the Future and the Help BEAT campaigns. If you wish to leave the campaign please let us know.

July 2016

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Who we are: Research for the Future and the 'Help BEAT' campaigns

Research for the Future is a NHS-supported project to encourage people living in and around Greater Manchester to take part in local health research opportunities. Research for the Future consists of a series of 'Help BEAT' campaigns. Each 'Help BEAT' campaign invites people with a particular health condition to hear more about research going on into that condition.

As Research for the Future is funded by the NIHR Clinical Research Network: Greater Manchester, most of the research opportunities we offer are in this area. If you live elsewhere in England you are still very welcome to join, but there will be fewer opportunities to take part.

Welcome to Help BEAT Heart Disease

Research for the Future are delighted to officially welcome Help BEAT Heart Disease to our other successful campaigns, Help BEAT Diabetes and Help BEAT Respiratory Disease.



Help BEAT Heart Disease covers many different heart conditions and problems, including: angina, heart attack, heart failure and abnormal heart rhythms. The term 'cardiovascular disease' is also used to describe any disease affecting the heart or blood vessels (circulation). Around seven million people in the UK have heart disease.

Anyone over the age of 18, living in and around Greater Manchester with a heart disease can now register their details with us so we can let them know about local research opportunities taking place. If you, or anyone you know, would like to join please get in touch – our contact details are at the top of this newsletter.

Check out our new website!

We needed to redevelop our website, www.researchforthefuture.org to include all three 'Help BEAT' campaigns so we took the opportunity to refresh our look.

We hope you like it! The website now includes information about the different types of research we offer as well as studies that are looking for volunteers at the moment. If you have never taken part in research before and are wondering exactly what it involves then the 'case study' page where you can read about others' experiences is a great place to start.

Out and about

The Research for the Future team have been involved in a number of events across Greater Manchester over the past few months.



In March we had a stall at Bolton's Health Mela, a fun event to promote Healthy Lifestyles. We joined Diabetes UK at a number of their awareness roadshows and educational 'Living with Diabetes Days' in Burnley, Macclesfield and Manchester, encouraging people to get involved with diabetes research. We spent International Clinical Trials Day (20th May) at Tameside General Hospital where we promoted our three Help BEAT campaigns and, together with their hospital research teams, reassured people it's 'OK to Ask' about research. If you are organising an event and would like the Research for the Future team to join you please get in touch!



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Find us on Facebook:
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Spotlight on 'Types of Research'

When we ask people what they think research involves, the answer we often get is someone who wears a white coat and works in a laboratory! Whilst this may be true some of the time there are lots of other ways researchers carry out their work. In each newsletter we will explain a bit more about one of the types of research offered by Research for the Future and give you an example of how our volunteers have helped. This time the spotlight is on interviews and focus groups.

Interviews and Focus Groups

Researchers use interviews when they want to find out, in detail, about a person's personal views or experiences about a particular subject. It is important that the researcher asks the right questions to find out as much information as possible about their chosen topic. 'Open ended' questions (need more than a yes/no answer) are best for this. Questions are usually prepared beforehand and tested on a small number of people first to make sure they are clear and easy to understand.

Interviews can be carried out face to face, over the telephone or in a group. A group interview is often called a 'focus group'. This usually involves about six to ten people who discuss the topic with each other as well as the researcher. This generates lots of interesting discussion and ideas. Telephone and face to face

interviews usually last up to an hour; group interviews a little longer. Sometimes the researcher or an assistant will make notes during the interview. Interviews are usually taped and written up afterwards so the researcher can refer back to exactly what was said.

Focus groups are popular in health research. Researchers often want to understand more about what it is like to live with a particular condition and find out what people think about the healthcare they receive.

This research can then be used to improve NHS services. Whilst interviews and focus groups provide researchers with a lot of detail about the subject, they are time consuming to carry out, so are unsuitable for large numbers of people.



How you've helped with interviews

We recently contacted respiratory and diabetes volunteers to see if they could help researchers at the University of Manchester who want to find out more about activity levels. They wanted to interview people with a long term condition and who were also low in mood. Researcher Isabel Adeyemi thanks everyone who contacted her to take part: ***"The response from 'Help BEAT' volunteers has been very good. I would have struggled to recruit so many people without your help. You have helped my study a great deal."***

Can you help?

Screening for families of people with type 1 diabetes

An international research programme called TrialNet wants to understand more about how type 1 diabetes develops and ways to delay or prevent it. Researchers are currently screening relatives of people with type 1 diabetes. A blood test can find out if they are at risk of developing diabetes years before symptoms appear. Family members of people with type 1 diabetes aged 3-45 years (parents, children, brothers and sisters) are eligible to be screened. Cousins, nieces, nephews and grandchildren may also be eligible.

If members of your family are interested in taking part and you live in or around Greater Manchester or Lancashire please contact Liza Swart, Research Nurse: Liza.Swart@wtcrf.nhs.uk or **0161 906 7500** (office hrs) or **0800 634 0102** (24hr answerphone).

If you live elsewhere in England you can find your nearest centre on the TrialNET website: www.diabetestrialnet.org.

Can you help?

Do you have type 2 diabetes? Do you have relatives in the Liverpool area who don't?

Researchers at University Hospital Aintree in Liverpool are looking at physical activity in people who have a family history of type 2 diabetes but do not have the condition themselves. Taking part in the study would involve your relative attending some clinic appointments at the hospital.

If you have a parent, brother, sister or child aged 18-60 years old who may be interested please ask them to contact Kelly for more information:

Email: K.BowdenDavies@liverpool.ac.uk
Telephone: **0151 529 5940**

Who we are: Research for the Future and the 'Help BEAT' campaigns

Research for the Future is an NHS-supported campaign which encourages people living in and around Greater Manchester to get more involved with health research in their local area. It consists of a series of 'Help BEAT' campaigns. Each Help BEAT campaign invites people with a particular health condition to find out about the research taking place into that condition. Joining Research for the Future means you will receive information about health research taking place in your area; occasional information about health events and a newsletter twice a year.



As Research for the Future is funded by the NIHR Clinical Research Network: Greater Manchester, the majority of research opportunities we offer are in this area. If you live elsewhere in England you are still welcome to join, but there will be fewer opportunities to take part.

A big welcome to our Help BEAT Respiratory Disease volunteers

In our last newsletter we told you that our first Research for the Future campaign, Help BEAT Diabetes, has been so successful that we have now started working with another health condition – respiratory disease. Respiratory disease includes conditions such as chronic obstructive pulmonary disease (COPD), emphysema and asthma.



Initial response has been really encouraging with around 100 people registering soon after the campaign launched. Our website is currently being upgraded so that people with respiratory conditions can register via the website. Once this has been done we'll be advertising the campaign a lot more so look out for us!

Anyone over the age of 18, living in and around Greater Manchester with one or more of these conditions can now register their details with us so we can let them know what respiratory research is taking place. If you, or anyone you know, would like to join please get in touch – our contact details are at the top of this newsletter.

Would your patient group like to hear about research?

Are you a member of a Respiratory or Diabetes patient group in the Greater Manchester area? If you would like one of our team to come and talk to your group about the benefits of taking part in research please get in touch.

We are also happy to supply posters and leaflets for you to take to your group. Together we can encourage as many people as possible to get involved in research!

Greater Manchester Clinical Research Network Awards 2015



The Research for the Future team were recently shortlisted to the Greater Manchester Clinical Research Awards 'Research Impact' category.

We were nominated for the positive impact the Help BEAT Diabetes campaign has had getting so many people involved in diabetes research over the past year.

The awards are designed to recognise hard-working and high achieving research teams from across the region, so we were absolutely delighted to be shortlisted! The team attended the awards evening in November. Sadly we did not win on this occasion but it was a privilege to be shortlisted and we had a wonderful evening.



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Salford Research Week a huge success

In September the Research for the Future team took part in Salford's Research Week. This annual event is organised by Salford Royal NHS Foundation Trust's Research and Development department. Members of the public had the opportunity to find out about the wide range of research taking place in Salford, meet some of the research teams and share their views at one of the many research roadshows.



The week started off at the 'We Love Eccles Festival' where we promoted the Help BEAT Diabetes campaign. The team really got into the spirit of this year's Alice in Wonderland theme and even made their own outfits for the event! Using some retro usherette trays, the team 'served up' lots of Information about diabetes as well as research studies currently looking for volunteers. The week was a success and great fun!



Spotlight on 'Types of Research'

When we ask people what they think research involves, the answer we often get is someone who wears a white coat and works in a laboratory! Whilst this may be true some of the time, a lot of people do not realise that there are lots of other ways that researchers carry out their work. In each newsletter we will explain a bit more about one of the types of research offered by Research for the Future and give you an example of how our volunteers have helped. This time the spotlight is on questionnaires.

Spotlight on Questionnaires

Questionnaires are a great way to start getting Involved in research as they are quick and easy to take part in.



It is widely thought that the questionnaire was first used by Sir Francis Galton in the mid 1800s. Born in Birmingham and half cousin of Charles Darwin, Sir Francis was an avid explorer and anthropologist who was particularly interested in human intelligence.

Paper based questionnaires are still used a lot, but as many people now have access to the internet, electronic questionnaires have become more popular. Questionnaires can also be completed over the telephone or face-to-face.

Researchers use questionnaires as a way of gathering information from a large number of people very quickly. The answers are then collected and analysed so the researcher can find out more about their particular area of interest. Before deciding to use a questionnaire, researchers need to make sure the questions they ask are easy to understand and think about who is completing it.

For example if a researcher wanted to gather opinions of elderly people with arthritis, it may not be a good idea to use a paper questionnaire. This is because hands are often affected by arthritis which might put people off completing it. The elderly may also have reduced vision which would make completing a questionnaire difficult.

How you've helped with questionnaires

In December we invited our volunteers to complete a short electronic questionnaire for Greater Manchester Patient Safety Translational Research Centre (GM PSTRC) at the University of Manchester. The questionnaire wanted to find out whether people had ever experienced any preventable mistakes whilst attending primary care (for example a GP, pharmacy, opticians or other non-hospital care). The researcher, Dr Jill Stocks, was amazed at the number of Research for the Future volunteers who took part;

'around 500 people completed the questionnaire in less than a week. It's wonderful to hear from so many people. By sharing their stories people have really helped our research'.

If you want to find out more about GM PSTRC

visit: www.gmpstrc.nihr.ac.uk

or sign up to receive their quarterly newsletter

at: www.bit.ly/GMPSTRC



This year over 1000 of you have taken part in a research study after hearing about it from research for the Future. A very big 'thank you' to you all!



Please do not be disheartened if you have not yet had chance to take part in any research, new studies are being added all the time!

HELP DIABEATES

NHS
**National Institute for
Health Research**
Clinical Research Network
Greater Manchester

July 2015
Research for the Future
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Help DiaBEATes focus on Greater Manchester

The National Institute for Health Research Clinical Research Network: Greater Manchester (NIHR CRN: GM) is one of 15 branches throughout England delivering NHS research in all disease areas. They are passionate about increasing opportunities for patients to take part in clinical research to help make a real difference to future patient care. One of the ways they do this is through the Help DiaBEATes campaign – telling you about diabetes research in your local area and how you can get involved. As the Help DiaBEATes campaign is a NIHR CRN: GM initiative, the focus of our work will now be across Greater Manchester and its immediate surrounding areas. If you live outside this area you are still very welcome to remain a member of the campaign. However there will be fewer research opportunities offered to you.

If you are happy to remain a Help DiaBEATes member you need take no further action. If you wish to leave the campaign, please contact the Help DiaBEATes team to remove your details from our database. Our contact details are at the top of this letter.

Thank you for being part of Help DiaBEATes

Dr John New is a Consultant Physician specialising in diabetes and obesity at Salford Royal NHS Foundation Trust and an Honorary Senior Lecturer at the University of Manchester. Dr New thanks all our volunteers for signing up to the Help DiaBEATes campaign and asks for your help to continue to spread the word.

Dear Help DiaBEATes volunteers,

Thank you for your on-going support into diabetes research. Your help is so important to everyone. Through research, we are able to find the best ways to help manage diabetes and thoroughly evaluate new treatments so they are safe and effective.

Taking part in research has been shown to have many benefits including greater understanding of your condition as well as knowing you are helping improve care for others in the future.

I wonder if I could ask you a favour? We are trying to find more people with diabetes who would like to hear about the different research studies going on.

If you know someone else with diabetes who might be interested in volunteering for research, please ask them to contact us by emailing helpdiabetes@srft.nhs.uk or by phone on: 0161 212 5574.

The more volunteers we have, the sooner we will beat diabetes.

Thank you all for your invaluable support.

Dr John New



Can you help find more volunteers?

Check out our new Facebook page and share our one minute promotional video, or your work or hobbies might give you a fun and novel way to spread the word!

We'd love to hear how you have helped promote Help DiaBEATes and will feature a selection of the best ideas in a future edition of the newsletter.

 follow us on Twitter
[@helpdiabetes](https://twitter.com/helpdiabetes)
We now have a Facebook page
 [helpdiabetes](https://www.facebook.com/helpdiabetes)

The DARE study

One of the most popular studies we have running in Greater Manchester at the moment is DARE. This study looks at genetic reasons why some people are more likely to develop diabetes than others.



DARE is classed as an 'observational study'. This means the researcher simply wants to observe certain things about you. You won't be given any medicines or tablets to take. Taking part in the DARE study involves one clinic visit lasting approximately one hour, during which you would have a blood test, height/weight and health questionnaire.

Anyone who has diabetes and is over the age of 18 can take part so it's a great way to start getting involved in research if you haven't done so before. The study is taking place across Greater Manchester so there is bound to be somewhere not too far from you!

Several hundred people have already taken part in this study - If you haven't yet and would like to, please contact the Help DiaBEATes team for further information.

Help Beat Diabetes.....and respiratory disease!



The Help DiaBEATes campaign has been so successful that we are now starting to work on another health condition alongside diabetes: respiratory and lung disease. This will include conditions such as chronic obstructive pulmonary disease (COPD), emphysema and asthma. As with diabetes, we'll be asking people across Greater Manchester who have these conditions to register their details with us so we can let them know what research is going on. Our work is part of a wider initiative to encourage as many people as possible to get involved in research and we will start using the name, '**Research for the Future**' as we begin to work with other medical conditions. Some of you may have noticed it on the address on this newsletter already! We'll keep you informed of our progress in future newsletters and tell you how you can get involved if you have respiratory disease.

Did you know?

It is estimated that 6% of the population has diabetes which means there are around 170,000 people living with diabetes in Greater Manchester, the majority of whom will have type 2 diabetes.



Help DiaBEATes volunteers make research study "a wonderful success"

The Help DiaBEATes team were recently approached by researchers from Liverpool University. They wanted our help to find one hundred patients who could help them understand how people with diabetes experience depression. We invited all our volunteers to complete the electronic questionnaire and over 400 of you took part, more than the researchers ever thought possible! Peter Fisher, Senior Lecturer in Clinical Psychology at the University of Liverpool, sends *"a very big thank you to all Help DiaBEATes volunteers who helped make our research such a wonderful success"*.



Out and about

The Help DiaBEATes team have been out and about across Greater Manchester at a number of events and venues over the past few months. In May, we were invited to join Diabetes UK at their Manchester 'living with diabetes day', held at the Lowry theatre. These free education days are aimed at people who are newly diagnosed with type 2 diabetes or who want to learn more about managing their condition. We really enjoyed the day and even got to try out some armchair exercises! We've also been involved with Diabetes UK 'know your risk' roadshows in Manchester, Blackburn and Wigan. We'll be at the Rochdale's Smith Street Car Park on 11th and 12th August so please come and say hello if you live locally!



Help improve research into patient safety in primary care...

The Greater Manchester Primary Care Patient Safety Translational Research Centre (GMPSTRC) is a unique research partnership between the University of Manchester and Salford Royal NHS Foundation Trust. GMPSTRC focusses on improving patient safety in primary care settings (e.g. GP surgeries and pharmacies etc.).



Find out about the world leading research being carried by GMPSTRC on their website www.gmpstrc.nihr.ac.uk or sign up to receive their quarterly newsletter, which includes opportunities for you can to get involved via: www.bit.ly/GMPSTRC

HELP DIABEATES

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The National Institute for Health Research (NIHR) Clinical Research Network is the clinical research delivery arm of the NHS. Following re-structure earlier this year, it now operates nationally across England through a national co-ordinating centre and 15 local branches to deliver NHS research across all disease areas. During the period of reorganisation there were many changes. This resulted in us not contacting you as often as we would have liked over the past year, for which we wish to sincerely apologise.

As a result of this reorganisation we recently moved to new offices. If you registered with us before August 2014 you may not have our new postal address (as shown above). Please take a moment to update this in your welcome pack. We can only contact you to take part in research studies if we have your correct details. If you move house or change your phone number or email address, please try and remember to let us know!



Have you ever wondered what it is like to take part?

Sam, a Help DiaBEATes volunteer, recently took part in her first research study and describes her experience here.

"When I arrived at the clinic I was welcomed by two diabetes research nurses. They showed me to a private room to complete the study paperwork. I was offered tea or coffee and made immediately comfortable and at ease. The nurses explained what would be happening at the appointment.

They described everything in detail and checked that I understood or if I had any questions, which was very reassuring. We read through the consent form together and I confirmed and signed each statement. Everything was very easy and relaxed. One nurse took my blood pressure, height, weight and other measurements. Everything was quick and painless. She asked me for consent to take a blood sample, advising how this would be stored and used for future studies if I agreed. We discussed my family medical history and my current health. Some of the questions were about my diabetes. The nurse explained she would contact my GP to get some further information with my consent, which I agreed to. My clinic visit was very relaxed and unhurried and I had lots of opportunity to ask questions. The nurses thanked me for taking part; however I would like to thank them for making my first experience of research so positive. I would be happy to take part in a study again".

Survey results

Earlier this year we sent out postal and electronic questionnaires to find out your experience of taking part in the Help DiaBEATes campaign. If you were one of the 306 people who responded then thank you very much for taking the time to share your views. Of the replies we received, we discovered that the majority of people (77%) were happy with the amount of information they received at the first telephone call to register with Help DiaBEATes and over two thirds of you thought there was sufficient information in the welcome pack you were sent following that call. However, there is still plenty of room for us to improve and we will be taking on board all your comments when we re-design our patient literature over the coming months.



Help DiaBEATes volunteers are 'a pleasure to work with'



Earlier this year Help DiaBEATes volunteers took part in a study at Manchester Metropolitan University to understand more about how the structure of the lower limbs affects walking in people with diabetes. It proved to be one of our most popular studies so far with ten people offering to take part in the first three days! A total of 30 people completed the study, which involved assessment of calf muscle strength and analysis of walking. The researcher, Milos Petrovic, paid tribute to the people who volunteered, describing them as 'a pleasure to work with'. He went on to say, "With these people's involvement, enthusiasm and support, I have been able to carry out my research very well. I really enjoyed spending time with Help DiaBEATes volunteers and have deep respect and gratitude for their help. These people really are 'big heroes'; ordinary people taking part in diabetes research so that science can discover new things and move forward"

"Being involved with the Help DiaBEATes campaign has been a very positive experience for me as a researcher".

Did you take part in this study ?
We'd love to hear your story !



Have you seen the

Help DiaBEATes website?

Two thirds of people responding to our survey told us that they hadn't yet visited the website. If you have internet access why not take a look?

www.researchforthefuture.nihr.ac.uk

Check out our new promotional video for GP surgeries in the 'videos' area.



Wishing you all the best for the coming New Year,
may it be prosperous and peaceful.

From all the team at

Help DiaBEATes



follow us on Twitter

@helpdiabeates

Working with Help DiaBEATes is inspiring!

Researchers at the University of Manchester's School of Psychological Sciences have been assessing hearing disability in people with diabetes. Participants were required to have their ears examined and undertake a series of hearing tests. Dr Maret Lepplann described her experience of working with Help DiaBEATes volunteers,

"Many of the people who took part in our study told us they did so in the hope that one day it will make a difference to others who have diabetes. We met some wonderful people who showed great interest in our research and were truly inspiring. We would like to thank everyone who took the time to take part. Words cannot express our gratitude".



Can you help?

The Help DiaBEATes team are currently looking for people who have taken part in research as a result of being part of the campaign. We would love to hear from you if you have attended focus groups, workshops or other studies. Taking part would involve telling us your story in a telephone interview. This would last no more than half an hour and be held at a time convenient to you. We are interested in your experience of the process, from your first contact with the researcher to what it was like to take part on the day. If you would like to be involved, please contact a member of the team at Helpdiabetes@srft.nhs.uk or telephone (0161) 212 5574 (24 hour answerphone facility).



Welcome

Welcome to the first edition of the Help DiaBEATes newsletter of 2014, providing you with up to date information about the campaign and research opportunities.

The Help DiaBEATes survey

We want to provide you with the best possible service. We are particularly interested in your experience of being part of the campaign and would be grateful if you could complete a short survey for us. This should take approximately 5 minutes of your time. You can access the survey on

<https://www.surveymonkey.com/s/HelpDiaBEATes>

If you have not registered your email address with us we have included a paper copy of the questionnaire with this newsletter.

New Study

Development of a tool to assess dietary habits of patients with type 2 diabetes

Some Help DiaBEATes volunteers with type 2 diabetes have been contacted about taking part in this study because of their experience of living with the condition. The study involved completing between two and four online questionnaires which will assist the researchers in the development of a dietary assessment tool to be used with people with type 2 diabetes. It is known that healthy dietary changes improve weight, blood glucose control, cholesterol levels and blood pressure. Ideally people with diabetes should receive individualised and on-going dietary advice and support from a health professional with expertise in nutrition, which is often a dietician. However in the UK access to a specialist service is not universal and other health professionals have both differing



Have You Given Us Your NHS Number?

We have recently had a new system installed at the Help DiaBEATes Contact Centre that helps us to link your NHS number to a system called FARSITE. If your GP has the FARSITE system at their practice and you have provided your NHS number we will be able to tell if you would be suitable to take part in different types of clinical studies.

Every research study has criteria that you need to meet to take part. These criteria can be very simple, for example you need to be a certain age or have a certain type of diabetes. As you provided this information when you registered with the Help DiaBEATes campaign we can contact you for these types of studies even if you have not provided us with your NHS number.

More often the criteria for a study can be quite complex, for example based on your past medical history or which medication you take. If

levels of nutritional knowledge and time that they can devote to this. Traditional approaches to assessing dietary habits are time consuming however short dietary assessment tools have



been developed in other countries for other conditions. The aim of this study was to develop this type of tool for type 2 diabetes to be used specifically in the UK. Clare England, Research Dietitian, NIHR Clinical Doctoral Research Fellow, University of Bristol explained, "I am

developing a short dietary assessment tool for people with type 2 diabetes. This will be used by people with diabetes and health professionals to quickly see which dietary changes could be made and make it easier to target advice. Working with the Help DiaBEATes campaign enabled people with diabetes who were interested in participating in research to become involved and help me develop this tool. I would like to thank the Help DiaBEATes team and all the volunteers who have participated. Your input has been hugely valuable."

Tell us your story

If you have been offered and have taken part in a study offered through the Help DiaBEATes campaign and would like to tell us your story we would love to hear from you. Contact us through the details below.

Keep in touch

If any of your contact details change please let us know. Our contact details are in the pack you received when you first registered, or below on this newsletter, or you can contact us <http://www.researchforthefuture.org/contact-us/>

We hope you had a good Christmas and we would like to take this opportunity to wish you all the best for 2014. With your support we hope this will be another successful year for Help DiaBEATes and diabetes research.

you have provided your NHS number to the Help DiaBEATes campaign, researchers can use FARSITE to see if you meet these more complex criteria. The great thing about the FARSITE system is that the researchers can never see your personal information and they do not know your name. Only your own GP has your personal information and medical history and they can let the Help DiaBEATes team know if they can contact you about the study. The Help DiaBEATes team will never be able to see your actual health record. When the Help DiaBEATes team contact you, you will have the chance to find out more about the study before deciding whether you want to take part and be put in contact with the researcher.

For example, in the early part of this year, the University of Manchester will be looking for people who have diabetes and diabetic eye disease but who have not previously had any problems with their heart. We can use FARSITE to anonymously search medical records to tell us how many people who have signed up to Help DiaBEATes may be able to take part.

If you are happy for us to hold your NHS number on our database and have not yet provided it you can do this by contacting the Help DiaBEATes team using the contact information supplied in this newsletter. We would like to assure you that data protection is of the highest priority to us. Everyone working for the NHS has a legal duty to keep information about you confidential. Any information you give to us is held on a secure NHS database and access to it is strictly limited.

[follow on Twitter](#) | [friend on Facebook](#) | [forward to a friend](#)

Help DiaBEATes, 3rd Floor Sentinel House, Albert Street, Eccles, Manchester, M30 0NJ
Email Helpdiabetes@srft.nhs.uk



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HELP DIABEATES

Thanks for signing up

Welcome

Welcome to the Summer edition of the Help DiaBEATes newsletter, providing you with up to date information about the campaign and research opportunities.

We have just launched our new website with all the latest information about research into diabetes and how you could get involved. Visit www.researchforthefuture.org



Professor Martin Gibson, Clinical Lead for the North West Diabetes Research Network, helped set up the Help DiaBEATes campaign and has been overwhelmed by the response. He explains: "We've been really impressed with the response to our Help DiaBEATes campaign—it's fantastic that so many people are willing to help find new ways of treating and caring for people with diabetes. Research is a real team effort. Clinical researchers and scientists can only make sure new therapies are effective and safe with the help of patients. We want to make sure that people in the UK are among the first to get the benefits of new research and access to the very latest treatments. Being a part of Help DiaBEATes is a great way to make sure this continues to happen. Thanks again to everyone for their continued support and participation".

National Diabetes Audit

The Help DiaBEATes team are currently undertaking a telephone survey on behalf of Diabetes UK and the National Diabetes Audit team. The survey aims to help researchers understand what people with diabetes think about the healthcare they receive. Over 200 of you have completed the survey so far to tell us what is going well and what needs improving with your care. Many thanks to those of you who have already taken part and shared your views. The encouraging news is that most people (75%) are happy with the care they are receiving but we know there is still room for improvement in many areas.

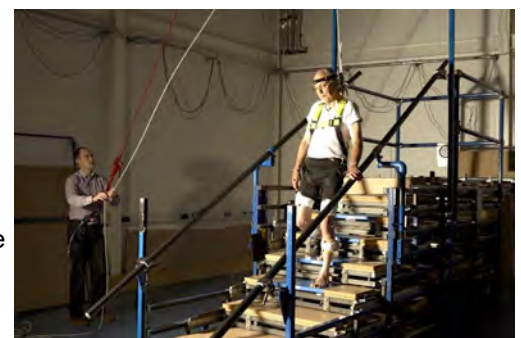


Laura Fargher, National Diabetes Audit engagement manager appreciates your input with this. She said: "The National Diabetes Audit (NDA) is delighted to be working with the Help DiaBEATes campaign to pilot our diabetes patient experience survey.

Later this year, the NDA is hoping to roll out a national patient experience survey, giving all patients an opportunity to feed-back on their experiences of diabetes care. The work that the Help DiaBEATes team are doing with the volunteers is providing us with valuable feedback on the questionnaire and patient experience, which will help inform the national rollout. A big thank you to the Help DiaBEATes team and all the volunteers who have participated so far."

The GAIT Study

Volunteers from the Help DiaBEATes campaign in Greater Manchester may have been contacted about taking part in the GAIT Study being carried out at Manchester Metropolitan University. The study aims to examine why diabetic peripheral neuropathy (nerve damage in the legs and feet) affects some people with diabetes, causing them problems with everyday tasks such as walking, going up or down stairs and getting out



of a chair.

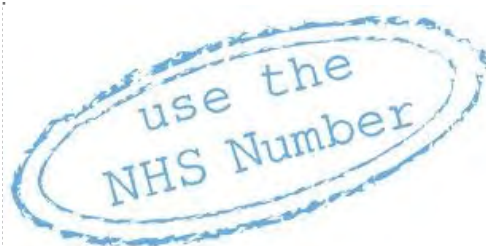
Researchers hope that by understanding how peripheral neuropathy causes increased risk of falling, they will be able to offer suggestions about how best to train leg muscles to reduce unsteadiness when walking. Working with a group of volunteers from Help DiaBEATes, researchers have already helped patients improve muscle strength by teaching them various different exercises.

Researcher Joe Handsaker said: "This has been a very interesting study and on behalf of our research team, we would like to thank all the participants who have both taken part, and expressed an interest in participating. Thanks to your participation and enthusiasm



throughout the testing process we are starting to uncover some incredibly interesting results." For more information on the GAIT study please visit www.researchforthefuture.org

Have we got your NHS number?



If you provide us with your NHS number it allows us to safely match you to a wider range of diabetes research that you may be suitable for. We will never be able to see your actual health record but we may be able to use your NHS number to search anonymously and see if you match the specific requirements of a study. Your GP will confirm that the Help DiaBEATes advisor can call you to tell you about the study.

We would like to assure you that data protection is of the highest priority to us. Any information you give to us is held on a secure NHS database and access to it is strictly limited.

You can still be part of the Help

DiaBEATes campaign if you do not give us your NHS number because some studies do not need to know any more about you other than the basic details you gave us when you registered. Examples of such studies are questionnaires or giving your



opinion on blood glucose meters.

You are never under any obligation to take part in any research that the Help DiaBEATes team inform you about.

Your care with your diabetes care team will not be affected by your decision. If you are happy for us to hold your NHS number on our database and have not yet provided it, please contact us and let us know.

Update your details

If your circumstances have changed or you've changed your address or phone number, please let us know so we can keep you informed about Help DiaBEATes.

Call Us: 0161 212 5574

Email Us: helpdiabetes@srft.nhs.uk

Visit www.researchforthefuture.org

Write to Us:

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News from the Diabetes Research Network

ISSUE 01 November 2012

Aims of the Diabetes Pathfinder Project

The NIHR Diabetes Pathfinder Project was launched in September 2011 with the aim of enabling people who want to take part in diabetes research to access studies that they are eligible to take part in. The project, a partnership between Greater Manchester CLRN, the Diabetes Research Network and North West E-health has the objective of delivering improvements to recruitment to diabetes research studies, enabled by rapid feasibility and a large consent for approach database of people with diabetes who want to take part in research. The project has two elements :- The Help Beat Diabetes Campaign and the FARSITE GP pilot.

The Help Beat Diabetes Campaign

Help Diabeates - BBC News 7 Oct 2011



The campaign was launched on the 7th October 2011 with a feature on the BBC News at One. So far to date 1,135 people have registered their interest to take part. People can register via a website or by text

Text :- RESEARCH to 81400

Website <http://www.researchforthefuture.org>

The campaign is also using social marketing and has a twitter account @helpdiabeates

Once a person has registered their interest to take part they are called by the contact centre staff who explain the campaign and complete their database record.

When a study they may be eligible to take part in becomes available, the contact centre calls the person to outline the study. If they are interested in hearing more about it they can be put in touch with their local research team. The volunteers also receive quarterly newsletters and general information about diabetes research.

Project Team Members

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 - Sue Hawksworth
 - Joanne Jackson
 - Julie Norrey
 - Eleanor Oakley
 - Susan Wilde



FARSITE GP Project

The aim of the GP FARSITE pilot is to use the FARSITE application in GP practices to help with recruitment to diabetes studies. The FARSITE application uses data from the GP patient record but preserves patient confidentiality by limiting the information given to researchers whilst still allowing them to see anonymised feasibility for a study. Researchers can use the FARSITE feasibility view to see the numbers of people matching each criterion of a study protocol. The FARSITE recruitment view gives control for trial recruitment to the GP. The GP can view all study documentation and a list of re-identified patients for their own practice and decide who should be invited to take part.

The screenshot displays the FARSITE application interface. On the left, there is a sidebar with a 'Protocol Templates' section containing a 'Load Templates' button, and a 'Study Overview' section with links for 'Stats', 'Approved', 'Study Members', 'Test (Chart)', and 'Incy (Letter)'. The main area is titled 'Inclusion Criteria (Match All Inclusion Groups)' and lists two criteria: 'I1 Include: Diabetes mellitus type 2' and 'I2 Include: Measurements'. Below this is an 'Add Include Group' button. The 'Exclusion Criteria' section lists three criteria: 'E1 Exclude: Palliative Care (GP Register)', 'E2 Exclude: Heart Failure (GP Register)', and 'E3 Exclude: Cancer (GP Register)'. There is an 'Add Exclude Group' button. At the bottom, the 'Demographics' section shows filters for 'Age' (Lower Age 50, Upper Age), 'Gender' (Any), and 'Ethnicity' (Any).

North West GP's linked to FARSITE

50 practices from Cumbria and Lancashire CLRN

50 practices from North and East Yorkshire and North Lincs CLRN

All Salford GPs

8 practices from Manchester

How FARSITE is used

The Pathfinder Project Management team (Sue Wood and Pam Tetlow) receive a protocol for feasibility from the DRN Coordinating Centre. The protocol is entered into FARSITE and figures are provided to the company/ researcher about the potential numbers of people who may be eligible to take part from the participating practices. This can help the company/ researcher to determine if the study is feasible to conduct within the UK. If the study is going ahead in the UK the study can then be sent to the GP practice via FARSITE and the practice can complete an Expression of Interest form if they want to take part in the study themselves or as an Expression of Collaboration Form if they want to identify participants for other study centres (PIC site)

“Enabling people with diabetes who want to take part in research to access studies that they are eligible to take part in”

GP Levels of Involvement

Feasibility Only – practice data adds to the information about whether a study is feasible in the UK

Participant Identification Centre - invite their eligible patients via FARSITE to take part in a study at another site

Research Site – use FARSITE to invite eligible patients to take part in a study at their own practice



The Diabetes Research Network is part of the National Institute for Health Research Clinical Research Network, which supports research to make patients, and the NHS, better