

### A fond farewell to key staff

**Marie Pitkethly**, the East Node Network Research Coordinator retired at the end of May after nearly 20 years' involvement in Primary Care Research Networks in Scotland. Marie became the TayRen Co-ordinator in 2000 which then became EastRen in 2004. In 2007, Marie became research co-ordinator of the East Node (Fife/Forth Valley/Tayside) of the Network facilitating the recruitment phase of research studies. Marie was also part of the team working on the update to the Cochrane systematic review on recruitment to trials. Marie has made a huge contribution to primary care research over a number of years and will be greatly missed by us all.



**Alison Hinds** is leaving the network this June after 10 years in post as the national manager. Her husband is retiring and she is moving to the South East of England to be closer to family. Alison has worked in medical research for 30 years after completing a PhD in Nutrition and Immunology at Kings' College, University of London. Alison worked at the Chief Scientist Office for 5 years from 2003 as NHS Programmes and Primary Care Manager and was seconded as research manager of the Scottish School of Primary Care from 2008, taking this up as a permanent post from 2009 when she became network manager of the Scottish Primary Care Research Network (latterly NRS Primary Care Network). We will really miss Alison but wish her all the best for her next adventure!



### A warm welcome to our new network administrator

**Jen Currie** joined the network as Administrator in January 2018. Jen worked for a Tayside Third Sector drug & alcohol support charity as a receptionist from 2007. She gained an SVQ3 in Business Administration in 2012 and became responsible for HR Administration and Database Management by the time she left the organisation in 2017. Any communication regarding practice payments or research charges, contact Jen.



### Congratulations Kim on your new role

**Kim Stringer** was recently appointed as East Node Research Co-ordinator following Marie's retirement. Kim has built up many years of experience within the network as Research Officer and we hope she enjoys this new challenge. Well done Kim!



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## NRS Primary Care Network: Research update

Below are recent ways in which the network has been utilised in order to facilitate recruitment.



### Primary Care intervention publishes results and produces recommendations for clinical practice

The NRS Primary Care Network facilitated the recruitment of GP practices across Scotland to the **DiRECT** trial. Forty nine practices across Scotland and Tyneside were randomised to either the weight-management intervention or the control group and there were 149 patients in each group. The trial aimed to assess whether intensive weight management within routine primary care would achieve remission of type 2 diabetes. The trial results were recently published in the Lancet (see link). Almost a quarter of participants in the intervention group achieved weight loss of 15 kg or more at 12 months, half maintained more than 10 kg loss, and almost half had remission of diabetes, off antidiabetic medication.

The researchers state that “this large primary care-based trial shows that a professionally supported intensive weight management programme is attractive to many people early in the course of type 2 diabetes. The programme allowed almost half of participants to revert to a non-diabetic state, off antidiabetic drugs at 12 months, and 68% stopped antihypertensive medications with no rise in blood pressure”. The team advocate that this type of intervention could be implemented within primary care and that “the potential personal and health-service-related benefits are considerable”.

Access the article here: <https://www.sciencedirect.com/science/article/pii/S0140673617331021>

As well as recommending this approach as a practical intervention within primary care, the authors make further recommendations for improved recording of change in diabetes status. In their Sept 2017 BMJ article (see link) the authors discuss the lack of recording / coding by GP practices when patients do achieve reversal of their Type 2 Diabetes diagnosis. They highlight the potential benefits to patients and the health-service that improved recording could bring.

Access the article here: <http://www.bmj.com/content/bmj/358/bmj.i4030.full.pdf>



### The FAST trial publishes results and informs decisions regarding the use of self-management plans for Asthma

The NRS Primary Care Network coordinator in Grampian was involved in recruiting for an NIHR / Asthma UK study looking at whether an asthma self-management plan that advised a temporary four-fold increase in the use of a steroid inhaler, when asthma symptoms started to worsen, could prevent asthma exacerbations.

The trial team found that using this self-management plan resulted in fewer severe asthma exacerbations than a plan in which the dose was not increased. Full study results have been published in the New England Journal of Medicine and can be found here: <http://www.nejm.org/doi/full/10.1056/NEJMoa1714257>

## NRS Primary Care Network: Research update continued...

Below are recent ways in which the network has been utilised in order to facilitate recruitment.



### NRS Primary Care Network provide support in raising awareness and encouraging GP participation

For a recently recruiting study '**Describing the brain tumour diagnostic pathway and patient-related diagnostic intervals**' the network across Scotland (Lothian, Forth Valley, Fife, Borders, Dumfries & Galloway) have been involved in recruiting *GPs* rather than patients. The network contacted GPs and Practice Managers to detail the study aims in advance, in order to increase awareness and gain support for the study. GPs were then sent a questionnaire to complete.

The study was assessing the time from first onset of symptoms to diagnosis (the diagnostic interval) for adult patients with brain tumour referred to a tertiary neuro-oncology centre. They had analysed hospital records of patients diagnosed with a brain tumour over an 8-year period and subsequently wanted to contact these patient's primary care teams to clarify their clinical symptoms and management prior to referral for hospital assessment. The data gathered will be used to identify whether there are groups of symptoms that might help doctors diagnose brain tumours earlier.

GPs were asked to provide data via questionnaire. This included the symptoms necessitating a visit to the health care professional and their length of duration, date of first appointment, number of visits prior to referral for imaging/specialist assessment in secondary care and management provided for the symptoms in primary care.

**At present, the response rate from GPs is over 86%, which the researchers attribute in part to the use of this awareness-raising approach by the NRS Primary Care network.**



Antihypertensive Study

### 'TIME' researchers highlight the contribution of the research networks in recruitment success

The Treatment In Morning versus Evening (TIME) study is a British Heart Foundation (BHF)-funded clinical study comparing morning dosing of usual hypertensive medication with evening dosing to determine if one is better than the other in terms of cardiovascular outcomes. This is an example of a secondary care-led study, recruiting the majority of patients through primary care due to the nature of hypertension management and access to eligible patients.

The NRS Primary Care Network invited 38 597 patients in Scotland to take part in the TIME study. In the paper published in 'Trials' (see link) the researchers highlighted the role of the clinical research networks both in Scotland and across the UK in facilitating the study to reach its ambitious recruitment targets (21,116 participants were randomised in total) in a cost-effective manner.

"The largest number of TIME participants were recruited from GP practices that had sent individual letters inviting patients to register on the study website. .... Participants clearly responded positively to letters from their own GPs' practices. .... Involvement of the NIHR Clinical Research Network and the Scottish Primary Care Research Network was invaluable in achieving this".

Access the article here: <https://trialsjournal.biomedcentral.com/track/pdf/10.1186/s13063-017-2318-4?site=trialsjournal.biomedcentral.com>

## GDPR compliance in relation to research activity

The new General Data Protection Regulation 2016/679/EU, took effect from 25<sup>th</sup> May in 2018 in all EU member states, replacing the existing data protection framework under the EU Data Protection Directive. The GDPR aims to strengthen the rights of individuals to be better informed about how their data is to be used, emphasising the transparency and security of personal data across the EU.

Under new GDPR regulations, the **legal condition for using personal data to identify eligible patients for research is: data processing carried out ‘for the public benefit’**

6(1)(e) – Processing is necessary for the performance of a task carried out **in the public interest** or in the exercise of official authority vested in the controller.

### Privacy Notice

To comply with the regulations, and fully inform patients attending practices where we assist in identifying eligible patients for participation in research studies, **we would ask that you add the below Privacy Notice Statement to your existing notice and/or display in waiting areas.**

### Patients who opt out

In order for us to exclude patients that have requested not to be contacted about research, the **read code 9Ndd** (Declined consent for researcher to access clinical record) **or 9Nu0** (Dissent from secondary use of GP patient identifiable data) should be added to the patient’s medical record.

### Network & Vision Log-in

To maintain a clear audit trail we will, from the 25<sup>th</sup> May, need our own Network login for Vision/EMIS or, if this is not feasible, the use of a locum login.

### MoU

We will also soon be sending a Memorandum of Understanding to practices that participate in research. This will detail the work we do on behalf of the practice and the way confidential data is handled in accordance with Data Protection Regulations.

## Privacy Notice Statement: [practice name] participation in research

As a practice, we feel that research is essential for progress in healthcare and is of considerable benefit to individual patients and the public as a whole. We regularly take part in research studies with the help of experienced NHS staff who search medical records for people who might be suitable so that we can write to them asking if they are interested in taking part.

No personal identifiable data is removed from the NHS or provided to any researchers without specific consent from patients.

Patients have the right to opt out of being contacted about research studies. *Please let the reception staff or your GP know if you wish to opt out.*

If you have any questions, please ask to speak to the Practice Manager

Name: ....

Tel: ....

Email: ....

To access the full NHS [Insert appropriate healthboard] Privacy statement please go to [link to Data Protection Notice on practice website].

[Insert NHS Research Scotland and local healthboard logos]

The **NRS Primary Care Network** was established in 2002 to co-ordinate national research activity in primary care. We are funded by the Chief Scientist Office (CSO) with the overall aim of increasing the amount of research relevant to patient care which is undertaken in a primary care setting. This involves network staff facilitating high-quality research studies, both academic and commercial across the full range of physical and mental health areas. The network contact information is below.

Node	Health Boards covered	Staff	Email address
National Team		Alison Hinds, Network Manager  Jennifer Currie, Network Administrator  Dr Bruce Guthrie, Primary Care Clinical Research Champion	a.hinds@dundee.ac.uk  nrsprimarycarenetworkadmin@dundee.ac.uk j.y.currie@dundee.ac.uk  b.guthrie@dundee.ac.uk
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West	NHS Greater Glasgow & Clyde NHS Ayrshire & Arran NHS Lanarkshire NHS Dumfries & Galloway	Tracy Ibbotson, Node Co-ordinator  Yvonne McIlvenna, Node Co-ordinator  Janice Reid, Research Officer	tracy.ibbotson@glasgow.ac.uk  yvonne.mcllvenna@glasgow.ac.uk  janice.reid@glasgow.ac.uk
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**Visit us at [www.nrs.org.uk/primarycare](http://www.nrs.org.uk/primarycare)**