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Belfast grandmother helps launch new report which shows patient input is crucial to designing COVID-19 research

A GRANDMOTHER-OF-EIGHT, from Belfast, has been helping to launch a new report which shows involving patients in the design of studies is crucial to COVID-19 research.

Dr Jackie Granleese, a mother-of-four and member of Public Involvement Enhancing Research (PIER) NI, joined a number of patients and public contributors to launch a new report by the Health Research Authority working with Health and Social Care Northern Ireland (HSCNI).

The report shows that patient involvement in COVID-19 research is crucial, adds value and is not just 'a nice to have'. It demonstrates the high value of involving patients in COVID-19 research both in terms of recruiting patients to trials and retaining them, as well as adding value to the topics being investigated.

The HRA is now calling on more sponsors and funders to play their part with clear and consistent leadership and to insist on patient involvement in their COVID-19 and other health and social care research studies.

At the start of the pandemic just 22 per cent of COVID-19 studies had consulted patients in the design of their study.

The HRA worked with partners to rapidly set up a COVID-19 matching service which linked researchers with public contributors who could provide feedback and input into COVID-19 research studies at speed before they came to the HRA for approval. This service along with other interventions has helped to jump-start patient involvement and by August over 85% of COVID-19 studies were involving patients, helping to improve health and social care research.

The new report entitled ***Public Involvement in a Pandemic: lessons from the UK COVID-19 Public Involvement Matching Service***, reflects on how that huge improvement in public involvement was achieved.

'I think people/patients can bring perspectives with fresh eyes to what is being done. They bring their experiences – particularly if they've suffered from what they're looking at or reading about. I think the systematic involvement of the public is critical in the co-creation of relevant research.'

'The new report is very important in highlighting the benefit of involving patients and members of the public to researchers. I hope in the future more researchers will realise the many benefits of involving patients and members of the public in their research.'

Professor Sir Terence Stephenson, HRA Chair, said: 'Public involvement is important, expected, and possible, even in a public health emergency. Our report clearly shows that when patients and the public are involved in designing research studies it helps to make research better.'

'Public involvement should not be 'a nice to have'. We are calling for sponsors and funders to do what was achieved by the COVID-19 matching service - showing leadership and making it clear that public involvement is 'business as usual'.'

Dr Janice Bailie, Assistant Director, HSC R&D Division, Public Health Agency NI, said: 'HSC R&D Division believes strongly in the value of involving patients and the public as partners at every stage of the research process. This report reinforces that belief and we are delighted that colleagues from our Public Involvement Enhancing Research (PIER) group in Northern Ireland were able to participate in this work.'

The report captures views from researchers and public involvement contributors on the impact of the matching service and the involvement that it enabled.

One pharmaceutical trial manager using the service said: 'We're really happy to use the service because at the end of the day these trials are for the patients, so if they're not reader friendly they're not user friendly, [and] then it does down the line affect our recruitment and retention strategies as well.'

The report calls for strong leadership and collaboration across the whole research system, supported by good communications and information, to ensure that public involvement plays its part in successful research, whatever the circumstances.

Juliet Tizzard, Director of Policy and Partnerships at the HRA, said: 'The collaborative effort to establish and run the matching service has demonstrated that the system has the capacity to respond appropriately to support the involvement of the public proportionately and effectively regardless of the circumstances.'

'It showed that with effective system-wide collaboration, communication and information, public involvement was able to become 'business as unusual'. If that can be maintained, then there is no reason why public involvement should not be business as usual for the sponsors and funders of all health and social care research in the UK.'

ENDS

For further information or an embargoed copy of the report, please contact Alison Barbuti, Communications Manager, on alison.barbuti@hra.nhs.uk or call 0207 104 8001 / 07880 174 592.

Notes to editors

For media enquiries please contact Alison Barbuti, Communications Manager at the HRA on communications@hra.nhs.uk or call 020 7104 8001 / 07880 174 592.

About the HRA

The HRA is one of a number of bodies responsible for the regulation and governance of health and social care research in the UK.

Our primary role is to protect and promote the interests of patients and the public in research, as well as to streamline the regulatory process.

Researchers wanting to undertake a study apply to us for HRA Approval, which brings together the assessment of governance and legal compliance, with the Research Ethics Committee (REC) opinion to confirm whether a research study has all the necessary approvals in place from the relevant bodies to proceed.

In the case of clinical trials, this also includes approval from the Medicines and Healthcare products Regulatory Agency, which is responsible for clinical trial authorisation.

The HRA is the appointing authority for RECs in England. We have formal responsibility for setting up and running RECs as well as appointing members, who provide independent opinion on research applications.

It is the responsibility of the REC to consider the ethics of a research application. More information can be [found on our website](#).