



2020

STH Clinical Research & Innovation Office Public Involvement Newsletter

**Welcome to Issue 4, Volume 2 of the PPI
Newsletter**

**Update from the Clinical Research & Innovation
Office**

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Update from the Clinical Research & Innovation Office

What a year **2020** has been for everyone; undoubtedly there have been **challenges** and **difficult times** and we **hope that you** and your families are all **keeping well**.

Earlier in the year, we shared a “COVID19” edition [newsletter](#); it is quite incredible to see how research both in Sheffield and nationally has progressed since then. On the 5th December, the National Institute for Health Research (NIHR) published an article highlighting that in approximately 8 months, over **600,000 people have taken part** in NIHR funded urgent public health research into COVID19 which is absolutely fantastic! You can read the full article [here](#).

Here at Sheffield Teaching Hospitals we have [over 30 trials](#) running that are **researching COVID19** including trials investigating **potential vaccines for COVID19**. You can find out more about this on the hospital website [here](#). In line with the [NIHR Restart Framework](#) (this supports the restarting of research paused due to COVID19) we have, and are continuing to **reopen non-COVID studies** that were **paused** due to the **pandemic** as well as setting up new studies. (*cont...*)

(cont from previous page) Since the start of the pandemic, we have all had to **embrace technology** and **learn new ways of working**, and fully understand the challenges this may have brought! We are **very grateful** to each and every one of you for continuing to be involved in research in Sheffield this year, and really **appreciate your commitment** by embracing these new ways of working, and sharing your experiences and feedback to help other groups take the plunge to **meeting virtually**.

Dipak Patel, Research and Innovation Manager in the Clinical Research & Innovation Office has this message to share with you:

“Public Involvement is vital in all health and social care research, and is valued by researchers across Sheffield Teaching Hospitals and The University of Sheffield as we know involving people with relevant lived experience can improve the quality and relevance of research.

Despite the challenges that COVID-19 has presented us all with, we are very grateful to you all for adopting new ways of working, learning new technologies to enable you to continue to be involved with research in Sheffield, and the time you have devoted to this during a public health crisis.

*I want to send a personal **“Thank you”** to you all.”*

Please let us know if you'd like to receive a **hard copy** of this newsletter.

You can **get in touch with us** using the contact details found on the final page of this newsletter.

For further information about Public Involvement at Sheffield Teaching Hospitals please visit: <http://www.sheffieldclinicalresearch.org/for-patients-public>



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Participant in Research Experience Survey

Each year, the NIHR asks people who have participated in NIHR health research about their experience of taking part so that improvements can be made. In the last quarter, 364 participants completed the survey at Sheffield Teaching Hospitals. **91%** said that they felt **researchers valued their taking part**, and **94%** said that they **would take part in research again**.

Crucially, **97%** said that the **information that they were given** before taking part **prepared them** for their experience on the study. This highlights the value and importance of involving the public in research including ensuring that information in Participant Information Sheets is suitable.

Here are just a few pieces of specific feedback about what was positive about participants research experience:

“Staff were friendly, approachable, respectful and polite”

“Felt participation was valued and appreciated”

“Potential to make a difference for the future”

International Clinical Trials Day 2020

Unfortunately, as with the PPI meetings, we have been unable to hold any face to face events this year. However, in the spirit of things this year we went “virtual” and held our **first online event**; this is very different from anything we have done before!

In celebration of **International Clinical Trials Day**, together with the Public Engagement team at The University of Sheffield, we held a **live discussion** on 24th June with **researchers** from Sheffield Teaching Hospitals NHS Foundation and The University of Sheffield about **“COVID19 Research in Sheffield”**.



Members of the **public** were invited to **submit** their **questions** about COVID19 research in advance, and many of these were **answered by our panel** of expert speakers.

Feedback from those who watched the event was **excellent**, and we were really grateful to our panel of speakers for taking the time away from their clinical & research commitments during the pandemic to speak at this event. We hope that those of you who watched it also enjoyed it, and found it both informative, and exciting to hear about the **breadth of COVID19 research** taking place across Sheffield.

Given how fast progress has been made with research into COVID19, some of the content may now be out of date, but if you did miss the event and wish to **watch it** you can do so [here](#).

Updates from panels and PPI members

Celebrating Ten Years!

Sheffield Emergency Care Forum (**SECF**), an independent PPI Group, is **celebrating 10 years involvement** with the School of Health and Related Research's (SchARR) Urgent and Emergency Care researchers.

In 2010 new Government guidelines stated that all health-based research should have patient and public involvement. Two people, already involved in SchARR research studies, decided to set up a formal PPI group. SECF held its first official meeting in April 2010 with just six members including a university student and an ambulance service representative.

In November **2010 SECF** was **launched** at the Injuries and Emergencies Specialist Group Research Sharing Day at The Source. It is thought that SECF was the **first PPI group dedicated to Urgent and Emergency Care research** in the UK.



As SECF celebrates 10 years, members can recall the multitude of studies they've been part of, initially as Steering Group members and more recently on Project Management Groups and as co-applicants. (See [here](#) for a list of studies and our networking).

Professor Ade Adebajo, INVOLVE Associate said:

*'SECF has exemplified excellence in patient and public involvement by **adding value throughout the research cycle**. I have been privileged to have encouraged the development of SECF following the INVOLVE Action Learning Sets. It is incredible just how much SECF has achieved over the 10 year period'*

Professors Suzanne Mason and Steve Goodacre said:

*"SECF has been **integral to the development of emergency care research in Sheffield** over the last 10 years. They have consistently **provided advice, support and insights** that have helped researchers to develop internationally important projects. SECF has also helped the personal development of researchers, by **providing advice and support** on educational projects and fellowships, and opportunities for medical students to work with the group. SECF has pioneered the development of public involvement in emergency care research and has helped researchers across the UK to involve the public in their activities. Thank you, SECF, for all of your help and hard work over the last 10 years!"*

SECF has 16 members who include University of Sheffield medical students and paramedics from Yorkshire Ambulance Service whose **help and advice we greatly value**. Members have a variety of backgrounds but all sincerely wish to see improvements in NHS services for the patients and public they represent.

It is always a **privilege to take part** in Centre for Urgent and Emergency Care Research (CURE) and other research studies as PPI representatives. Many thanks must go to the **researchers who value the patient and public perspective** and continue to provide members with opportunities to be involved in studies and to attend relevant conferences.

We would like to dedicate this article to the memory of our wonderful colleague and friend Rosemary Harper, who in 2010 was a founder member of SECF. After 10 years of service to the group Rosemary sadly passed away earlier this year.



The Age Gap Study

Three members of Yorkshire and Humber Cancer Research Panel (YHCRP) worked on Professor Lynda Wyld's research into **breast cancer in older women**, and their choices between surgery and endocrine therapy known as 'The Age Gap Study'. This was a **large multi-centre study** that aimed to address the issue of women over 70 having poorer outcomes than women under 70. One of the outputs was the **Age Gap Decision Tool**, available on the internet, and booklet. The tool can be accessed here <https://agegap.shef.ac.uk/>

Since its launch in November 2019 the tool has been **used in over 62 countries** across the world and we have **pleasing feedback** from many of the users. The tool was designed primarily for clinicians to **use in conjunction with their patients** in helping make the difficult decision between surgery and endocrine therapy or stand-alone endocrine therapy which is appropriate in some women.

So far, the study has generated 20 papers with more in production, and the **decision aid has been recognised and approved by MHRA.**

For PPI, the study commenced in 2014, and was undertaken by Deirdre Revell, Tracy Green, and Jacqui Gath.



Public Involvement in Cystic Fibrosis Research

By Sophie Dawson, Patient & Public Involvement (PPI) Lead for CF DigiCare, and Dr Martin Wildman, CF DigiCare Clinical Lead

Equity of access of under-served populations to digital interventions is a critical issue in the management of people with long-term conditions. CFHealthHub is a UK-wide multi-faceted digital behaviour change and self-care programme in **cystic fibrosis (CF)**. The CFHealthHub programme team were **awarded a grant** from the National Institute for Health Research Yorkshire & Humber Public Involvement Fund (RDS YH PIF) to **conduct a PPI project** to explore the **views of people with CF** who might be considered '**hard to reach**'. We were keen to explore how we could support more people with CF to take part in future CFHealthHub research studies; how we could **engage with patients** who might be considered 'hard to reach', and how we could support these patients to share their views in a PPI project.

What are the challenges faced by CF researchers and participants in being involved in research (such as via traditional face to face meetings)?

People with CF can never meet face-to-face due to the high cross infection risk. As such, it is not possible to conduct PPI in the 'usual' way (i.e. via face-to-face focus groups). PPI work involving this population therefore has to be **conducted via 1:1 interviews** with a researcher, over the phone, or using digital technology (e.g. online focus groups).

Another challenge is the **lack of funds** often available to support PPI work and to compensate patients for their time. We recently explored a PPI funding application, but this could only be used to fund travel expenses, venue hire and refreshments. None of these costs were applicable to people with CF who would not be able to attend a group face-to-face meeting. Instead, it would have been more beneficial if we could have used the funds to **compensate patients for their time**, but this was not part of the eligibility criteria. That's why we were so **grateful to be awarded** the RDS YH PIF to support this PPI project.



What novel approach did you take to involving people with CF in your research?

CFHealthHub is a national innovation and research programme being implemented in 17 adult CF centres across the UK. As we were keen to **explore the views of people with CF** who might be considered 'hard to reach', we initially had to develop some consensus in terms of what was meant by 'hard to reach'. We agreed that patients might be considered '**hard to reach**' if they **met one or more of a range of criteria** (e.g. three or more 'no shows' at CF clinics in the past 12 months; invited but declined to participate in CFHealthHub; less than 20% of treatments taken in the past three months; CFHealthHub self-care data sharing with CF team turned 'off' etc.)

We were keen to involve people with CF from different CF centres, so we asked the Local CFHealthHub Lead in each centre to identify people who met the agreed criteria. They then approached patients to ask if they may be interested in taking part in a 1:1 interview or online focus group. We were really pleased that **18 interviews were conducted** over a two-month period. I think it helped that patients already had a **good rapport** with the person interviewing them; it helped them to **talk more openly** as they trusted them.

Importantly, we recognised that although people with CF who were **less engaged** might not attend clinics, we could approach them when they were admitted to hospital for 'rescue therapy', or by **moving engagement** to the patients chosen "turf" e.g. via home visits. Although we originally anticipated that conducting the PPI interviews during home visits may be most appropriate for this population, most **interviews were conducted** when patients were **in hospital** for two-week courses of treatment. It's often easier to **involve people when it's convenient** for them (i.e. when an inpatient on a ward).



What difference did it make to both the research, and also to the patients themselves?

From a research perspective, it has been really valuable in terms of understanding the importance of paying attention to strategies that can be used to reduce the burden of trial participation. The **results** of the **PPI project** will shape strategies to **improve equity of access** to the CFHealthHub digital intervention in future research studies.

Patients seemed to **enjoy taking part** in the PPI interviews. It's easy to make assumptions about certain groups/ patients and whether they might want to be involved in something like a PPI project. However, just because people may be 'hard to reach'/ seldom heard and be deemed to have **low engagement** with their clinical care, **does not mean they don't care**; it's far more complex than this. Many people with CF were **keen to be involved** in research around this topic area and were happy to be asked to take part.

Is there any feedback from the patients that you can share with us?

Feedback is key – people are often involved and participate in research but invariably don't hear any follow up. It's therefore really important **for long term engagement** to ensure people's **contributions are valued** (e.g. share the results with patients after the PPI or research project has finished).

There is **no 'one size fits all'**, so we must adapt and personalise involvement requirements to suit the individual. Group activities can be overwhelming for some people, so patients may prefer 1:1 interviews; other people may not want phone calls but will email.

Twitter handle: @CFHealthHub

Website: <https://www.cfhealthhub.com/cfdigicare/>



What did you learn about this involvement that could be translated across into other patient groups or public involvement more broadly?

Flexibility in terms of the **approach** used is really **important**; meet patients on their terms to make it easy for people to be involved and want to take part. Try to **anticipate** possible **barriers** to engagement in advance, and then **think outside of the box** and use your initiative to overcome these barriers. One patient said they would be happy to take part in future PPI work but daytime activities would not be suitable for them. We therefore need to **consider** an **individual's** personal **circumstances** (e.g. how can we involve patients outside of the normal 9am-5pm?).

Be proactive in seeking out people who might like to be involved. Expecting people to respond to an advert means you are likely to get a self-selected group of people who respond. This doesn't mean that other people may not be happy to take part in PPI work if asked and if we make it as easy as possible for people to be involved.

What are your future involvement and engagement plans?

We were really pleased to **share** the **results** of this PPI project in a **poster** presentation at the North American CF **Conference** (which took place virtually this year). To support future PPI work and **ensure** the '**patient voice**' is **heard** across the CFHealthHub programme, we are now establishing a CFDigiCare PPI group. This will comprise a Patient Representative from each of the 17 CF Centres involved in implementing CFHealthHub across the UK.

Acknowledgements: Thanks to the people 18 people with CF who shared their views with us, to the six CF centres who took part, and to the people who contributed to this project (*Katy Lee, Peter Moran, Elizabeth Shepherd, Charlotte Carolan, Jayne Faulkner, Louise Warnock, Lizzie Walton and Madelynne Arden*). We are very grateful to the NIHR RDS Y&H who supported the public involvement work through their Public Involvement Fund



Opportunities for public involvement and participation in trials (local and national)

Have you been involved in health and social care research as a public contributor?

The National Institute for Health Research would like to **invite you** to participate in an **online survey** on **remote working** for **public contributors, advisers or experts by experience**. It will take about **20 – 30 minutes** to complete and is part of a study aiming to explore how they can **facilitate and improve** doing **patient and public involvement and engagement** in health and social care research, without direct face-to-face contact. [If you want to take part, please do so via the online survey by clicking this link.](#)

Sheffield group looking for new members

The **Reproductive Health Research Advisory Group** are looking for **new members** who have personal experience of:

- Gynaecological care
- Assisted conception (men or women)
- Maternity care (men or women)
- Hospital-based neonatal care (men or women)

More information about the group can be found [here](#). Interested individuals can contact Clare Pye on Clare.Pye1@nhs.net

Please share this opportunity with any friends, family or colleagues who may be interested - thank you.



Opportunity to join Trial Steering Group for Sheffield Study

The [Multiple Symptoms Study 3](#) are looking for a **patient representative** to join our **Trial Steering Committee**. This study is a large randomised controlled trial testing the **effectiveness** of a **Symptoms Clinic** for people with **persistent physical symptoms**.

Joining our Trial Steering Committee would mean attending about **two meetings per year**, currently these meetings are taking place **remotely** (either **telephone call or video link**). You will be **reimbursed for any expenses** to attend meetings and for your time. You would be **helping to advise** the research team from the perspective of someone with experience of persistent physical symptoms. The trial is already up and running so the types of things we may ask you to advise on may include changes to our current processes or we may ask you to review participant documents, such as letters or flyers.

Who are we looking for?

We are looking for a representative who has **experience of persistent physical symptoms**, where test results have come back negative. By “persistent physical symptoms” we mean symptoms which are there most days and which interfere with daily life. These may include: **Pain** or **fatigue**, or conditions such as **IBS**, **Fibromyalgia**, **Tension-Type Headache**, and **Pelvic Pain**.

This experience may be personally or through a close relative or friend. If you are **interested in the role** or have any questions, **please contact the Trial manager** Cara Mooney on multiple.symptoms.study3@sheffield.ac.uk. Please also provide some brief details about yourself including who you are and why you are interested in this role. We will use these details to select a suitable representative.



National Cancer Research Institute (NCRI) Consumer vacancies

The NCRI is currently **seeking patients**, carers and others **affected by cancer** (“[consumers](#)”) to represent the patient community on the following [NCRI Groups](#):

- Gynaecological Group
- Haematological Oncology Group
- Lung Group
- Living With and Beyond Cancer Group
- Sarcoma Group
- Teenage and Young Adults & Germ Cell Tumour Group
- Upper Gastrointestinal Group.

Before filling in an application, we **recommend reading** the [NCRI Consumer recruitment pack](#) in full, which outlines the key information needed to get involved with us. Please submit via the [application form](#).

If you have **any queries, please get in touch** with Chantal Ball (NCRI Forum Coordinator) via [email](#) or [phone](#).

The **deadline** for applications is **Friday 15th January**

Be Part of Research

This is just a reminder that you can find out more about health and social care research in the UK on the Be Part of Research website

<https://bepartofresearch.nihr.ac.uk/> .

There is also a link at the top of their webpage where you can find the **latest information about COVID-19 research**.



Health Research Authority – Invitation

Please **save the date** to join an online event about the UK COVID19 public involvement matching service – full details in the flier below.

Public involvement in a pandemic



Invitation

Join us to discuss lessons learnt from the UK COVID-19 public involvement matching service.

Register to join at public.involvement@hra.nhs.uk

13 January 2021 | 11-12.30pm | via Zoom



Contact Us in the Clinical Research & Innovation Office

We hope you have enjoyed reading this newsletter. **Thank you** for your contributions. If you've got any questions, comments or suggestions, you can **contact us** in the following ways:



<https://www.sheffieldclinicalresearch.org/>



0114 2711628 (Eve) (please leave a message as we are mainly remote working)



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@Shef_Research

