

# ISSUE 1, JANUARY 2021

# HEALTH LITERACY

# INTERVENTIONS NEWSLETTER

## Welcome

Welcome to our first project newsletter for the Health Literacy Interventions review. We wanted to give you an update every couple of months about the progress of the study. If you have any questions about the project or feedback you want to give, please get in contact.

Alicia O’Cathain, Alexis Foster and Margaret Ogden, on behalf of the team.

### Contact details

If you want to get in contact with the team, please contact:  
Alexis Foster, Researcher,  
Email: [alexis.foster@sheffield.ac.uk](mailto:alexis.foster@sheffield.ac.uk)

## Summary stakeholder event

In November, we held a virtual stakeholder event to discuss the study and to get feedback on our ideas. We were delighted by how many people attended. This included members of the public, clinicians, people from the charity/community sector and people who fund services (commissioners). The meeting helped us think about potential interventions including who may receive support, when and in what format. We also heard from NHS England about national health literacy initiatives including one that is helping people to feel confident about having routine operations in hospitals during the pandemic. We have sent out the notes from event; please let us know if you need a copy.

## Listing your name in the study’s report

We would like to name you as someone who has contributed to the study in the reports we write about the research. The reports will be publicly available. If you would prefer not to have your name included then please let Alexis Foster know by emailing: [alexis.foster@sheffield.ac.uk](mailto:alexis.foster@sheffield.ac.uk). We will have a general statement thanking everyone for their support within our reports.

## OUR STUDY:

Our study is looking at the existing evidence (both academic articles but also reports, presentations and other literature) to identify what interventions/initiatives have been used to improve people’s confidence (health literacy) to help them manage and make decisions about accessing care for non-urgent issues. For example, patients may receive leaflets about getting support from pharmacies rather than going to the GP. We will use our findings about what has worked to advise the NHS. The study is not about stopping people accessing services but it is about helping them to access the right support, at the right time.



## Welcome to Chris Carroll- New member of the team

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We are delighted to welcome Dr Chris Carroll to the team. Chris is an experienced reviewer who will be responsible for conducting much of the study. Chris has spent time looking at how best to bring together and make sense of information from different studies to inform the NHS. This knowledge will be very valuable for this study.



## Introducing Margaret Ogden- Patient Involvement Member of the Team

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Margaret Ogden is a key member of the study team because she represents the patient's voice and provides advice on making sure our study is both useful for patients/carers but also that we involve people within the project. Below are some words from Margaret about how she became involved and her background.

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## How I got involved in the project

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My involvement in this project was completely opportunistic. I met Alicia (the project lead) at a meeting in Sheffield. My contribution at that meeting must have been meaningful to her because the next thing I knew, I was invited to be involved in the study team. I jumped at the chance. The study is funded by the NIHR Health Services & Delivery funding stream.

I live in a deprived area of the north east – a former mining village where there are health and social care challenges, mostly historic from the coal mining industry, with heart and lung illnesses. There is low car ownership but it is a vibrant community – salt of the earth people who are always there to lend a hand. Particularly during COVID I have noticed literacy problems – people not always understanding the terminology around COVID as well as legalities and guidance. With regard to the Health Literacy Interventions project, we would be concentrating on patients with minor health problems.

Access to services can be difficult – I live within a 10 mile radius of three general hospitals. But I have to travel considerably further for more specialist hospitals. I was a carer of my 93 year old uncle and we have presented at A & E several times though some experiences have been better than others. Whenever he has fallen, he wants to go to hospital and I have been unable to deter him from this, no matter how hard I've tried. This was before the onset of vascular dementia and his admission to a local care home.

# History of my Patient and Public Involvement

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I became involved in Patient and Public Involvement within research when I developed a rare auto-immune illness, Wegener's granulomatosis. My knowledge of health at this stage was average, at best. When I was ill, my lack of health literacy soon became apparent. Thankfully my mother had been a nurse; I relied on her guidance as I started to make decisions regarding tests and treatments.

She died just as I was going in to remission and I had a severe episode of depression. I had psychotherapy which was helpful.

My first project was helping to produce guidelines on treatment of depression in people with chronic physical illnesses – right up my street! Working with eminent psychiatrists and physicians, my health literacy greatly improved. Other projects on cancer, palliative care, diagnostics, A & E, pharmacy followed. With regard to the latter, I now teach year 1 medical students at one of the London universities.

I have had training – I've learnt about equality & diversity, audit, governance, ethics, evidence synthesis & thematic analysis.

There has been an element of altruism in my work. Clinicians had made me well again – I wanted to give something back. Campaigning, fundraising & working with the homeless are my other interests.

When it came to the Health Literacy Interventions project, our start date was delayed slightly. But at start-up, I hit the ground running. I had experienced some stress during the application submission but the rest of the team were supportive. Then there was relief and delight on hearing we were successful. The researchers have been great at giving explanations in layman's terms – no easy ask. There is regular communication, often touching base in the interim between meetings. What has been the most exciting has been the Stakeholder event. We had meetings beforehand so I was well briefed. Attendees had already some understanding of the topic. Nevertheless language still needed to be straightforward. I monitored this throughout the event. A wide range of professionals attended – representatives from primary care, NHS Direct, NHS England, the Ambulance Services. There were also attendees from the voluntary sector as well as those speaking from a patient perspective. I had not used Googlemeet before but this went smoothly.

## Our current work

At the moment we are busy deciding which studies we are going to include in our review. Our information specialist: Mark Clowes (an expert in finding the studies) has searched for potentially relevant studies. Mark has identified over 6000 potential studies. We are now looking at each study to decide which include relevant information. We have also identified a number of reports from places like the World Health Organisation and local NHS trusts.

Alongside the studies we are also seeking to get hold of the interventions where possible e.g. information leaflets. We feel it will be useful to look at examples. In time, we hope to share these with you to get your perspectives on them. We will be considering how easy the interventions are to read and understand.

## Next Steps

Over the next couple of months, we will be choosing which studies we are going to be including in the review. We will also understand the type of interventions that have been evaluated.

We will update you on these in the next newsletter (Springtime).

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**The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.**