



**Sheffield Dementia Involvement Group**

**December 2023**

**Research**

**What's the point?**

## **Background**

In December we were joined by seven people living with Dementia and six carer/supporters. We welcomed two new members who are both carers. In our 'Tea and Talk' planning meeting in October we proposed 'research' as a topic, the group agreed this was a worthy of exploring. Questions were tried out and adapted by the planning group and the process of gathering existing experiences and opinions on research began.

December was our first meeting in a new venue, Ponds Forge. Several venues had been considered and had to be ruled out due to cost implications. One attendee kindly took part in an environmental assessment of Ponds Forge in advance to see if it would be an appropriate venue.

In addition to our discussions on research, each group were also invited to share their feedback on the new venue.

### **Feedback on the new venue**

Some people felt that Ponds Forge was hard to find and requested clearer signage. This will be provided using an A board outside the venue, along with a meeting point in reception and additional facilitators to guide people within the building. It was felt to be helpful to be greeted by familiar faces as people entered the main reception. Most people thought the space was comfortable and appropriate for sharing lunch and group discussions. The food was enjoyed, particularly the cakes and hot snacks. People appreciated the proximity of the venue to tram stops and that there was free parking available for attendees. The break-out rooms were large and rather cold. We acknowledged that we missed using the Quaker Meeting House but would be happy to use Ponds Forge again. Staff were kind and accommodating and amenable to adapt to meet the needs of the group.

# Summary

- Research can be for anyone.
- Research must have purpose for people to get involved.
- People want their contributions to be valued.
- SHINDIG attendees encourage each other to get involved in new opportunities.
- You are never too old to learn.
- Some people think research is for clever people.
- Several SHINDIG attendees are already involved in DRAiSY (Dementia Research Advisory Group South Yorkshire)
- The need to travel to be involved in research can be off putting.
- Online information doesn't work for everyone.
- Information about research needs to be accessible and not repetitive.
- People felt good if they could help others by being involved in research.
- People didn't always find out what happened with the research they had been involved in.
- People would like to see research on living with Dementia, preventing Dementia and the carers perspective.

# Main report

## What comes to mind when you think of research?

One person described research as

“Finding a blind spot and shining a light on it”.

A new member of the group came up with the following analogy.

“A picture in my head is of an unwieldy silk balloon filled with people and ideas trying to get out”.

One person felt that research was for ‘clever people’ and this ruled them out. Another shared having had similar beliefs but how their opinion had changed.

“I used to think it was for clever people, but it’s for everyone, your education doesn’t matter. The university of life is just as important. We’re learning all the time; you are never too old to learn”.

Others felt that research related to ‘the medical side of things’ suggesting that it was about.

“Finding a cure and medication that could slow the progression of the disease down”.

Some attendees recalled their involvement at a technology themed SHINDIG where they were invited to explore devices such as trackers and prototypes for instruments. People described having had a ‘fun afternoon’ but didn’t generally feel it was a useful experience for them.

A carer shared that her husband had donated his brain for Dementia research.

## What’s in it for you?

Making a difference for other people was deemed important.

“It would make me feel great if they came up with something to help. It would mean that something was happening for other people. So, they don’t have to go through what we did”.

Feeling valued for their contribution. One person stressed the importance of being acknowledged as Co-Author, Co-Researcher, Co-Designer. They acknowledged that some people would prefer to remain anonymous.

“You can opt in or opt out of being named”.

### **A sense of pride**

One person living with Dementia told us how he now keeps the findings from the driving research project he was involved on display for all to see.

“We had the findings made into a book that I keep on a pouffe in the living room”.

Voucher remuneration was mentioned as being used for people supporting Dementia research. People who had experienced this had appreciated the gesture.

One carer informed us that her husband had been involved in a research project that went on for a year.

“Taking part made his life a thousand times better”.

It was agreed that the research topic needs to be relevant and there should be clarity about why and how the research will be carried out.

“What are we doing? what is it working towards? Are there are ethics? who is funding the research and is there an agenda?”.

Several people shared frustration at having been involved in research but not learning the outcome.

At times people have felt used.

“People are now doing more co-production, which is good so long as it is not tokenistic”.

### **What stops you getting involved?**

Several people listed travel as something that could put them off. One person involved in national research stressed that negotiating public transport in other cities can be problematic.

There was a lot of discussion about accessibility. For some types of Dementia having things ‘online’ can result people feeling they have limited options of getting involved in things like research.

“I can’t read things easily, use a tablet or watch tv.”

The information provided, relating to the research can also cause problems.

“Information not given in the right way stops me taking part. I need materials in the right format and with enough time in advance to consider them.

“Information sheets, consent forms, sign them ten times. These present barriers”.

“I struggle with information presented on the computer, too much text, makes it too complex”.

### **Repetition**

“So much research has been wasted researching the wrong things. If I had a pound for every time, I’ve been asked how I have been affected by the pandemic”.

It was felt important that the research was legitimate.

“Is it bona fide research/researcher. Research results aren’t always genuine. Drug companies have falsified results. One danger is that there are some unscrupulous companies who are ruled by money”.

### **Have you participated in research?**

Among attendees, both people living with a diagnosis and carers/supporters are actively involved in research. Five SHINDIG attendees are members of DRAiSY Dementia Research Advisory Group South Yorkshire. Among many other things DRAiSY enable the person with a diagnosis and carers perspectives to be heard and provide knowledge for researchers based on lived experience.

Two people have been involved in the Dementia Enquirers programme which supported groups of people living with Dementia to conduct their own small scale research projects.

One of our new members shared that she is part of a research network and is involved with reviewing funding applications to the Alzheimer’s Society.

“We rate the ideas, seeing if the plans are viable. I find this very interesting”.

Another member of the group had done research during their career.

“I was the researcher not the participant, I enjoyed talking to people it was interesting and enjoyable”.

One member of the group listed a variety of research projects he has participated in on a voluntary basis. One of which resulted in the production of information packs about Dementia that were accessible to all.

“People with a diagnosis, their family and the professionals”.

He stressed that he would remain involved in research while ever he is well enough.

Another person living with a diagnosis shared how she remains involved.

“I still do public speaking, I have notes now. It gives me pleasure. I would want the results of any research I had been involved in to be properly disseminated with recommendations that are properly acted upon. I keep going until I get the information, a plain English summary. I participate where it’s realistic, we may never find a cure in our lifetime but things are progressing. I insist we have the results fed back to us”.

Some people commented on not always finding out the outcome of the research they had been involved in and experience of feeling patronised when information had been shared with them.

A conversation took place about involving people who may no longer be able to communicate verbally. The example was given of Sheffcare residents and families being involved in trialling communication kits and tools linked to music. It was suggested.

“For research to be valid we need to cast a wider net and be more creative in how we gather opinions”.

### **What topics do you think need to be researched?**

Some people considered how Dementia affects them personally.

“In practical terms, I would like research around sight difficulties and technology to help me”.

“I would like to know if it is hereditary as I have heard differing views”.

Others felt strongly about living with Dementia after diagnosis.

“We don't only need to focus on cure, focus on people living with dementia now. Making life better for people with dementia and their carers. care after diagnosis currently isn't good enough”.

“What about changes in lifestyle”?

Medication and preventative measures were also listed as topics that needed exploring further.

### **Awareness**

“There needs to be a positive plan for raising awareness the media only shares the tragedy narrative of Dementia”.

Research from the carer/partners perspective.

“I’ve gone from having a wife, a partner, being a team to now being full time carer. I would get involved if it would be useful, but I couldn’t go anywhere as I couldn’t leave her”.

Others agreed.

“Our families get the diagnosis too and have a very different perspective”.

One group discussed the subject of staying safe, acknowledging that Dementia can make people vulnerable. Two people had experience of being taken advantage of. They had been charged excessive amounts of money for work on their home.

One carer shared her story of her husband’s recent diagnosis and questioned if things could have been different.

“The timing of everything has been slow, he was diagnosed when it was already advanced. An earlier diagnosis could have delayed the progression. The symptoms were there for two years, they said he had Depression are there ways of getting an earlier diagnosis”.

“It’s about finding out then knowing what to do, there are so many steps to go through”.

This conversation led to a conversation about DAS the Dementia Advise Service.



## **Do you know how to get involved in research?**

“There is nothing stopping me, I would happily get involved if it were an interesting topic.”

Some people recalled that Memory Service informing them that they could get involved in research.

Discussion took place about the Join Dementia Research website. Our Tea and Talk planning group have previously taken part in a workshop to help redesign the website in order to make it easier to use.

One person was unable to use a computer due to sight difficulties so would prefer to be involved in person.

Stories shared by existing DRAISY members generated interest among the larger group and two additional SHINDIG attendees are now attending DRAISY meetings.

## Conclusion

This SHINDIG event offered people living with a diagnosis and carers/supporters the opportunity to share their views on research. Our two observers came from the Alzheimer's Society and Sheffield Hallam University. The group included people with a range of experience as researchers and participants and some with no experience at all. As with most SHINDIG events, peer support was evident throughout the afternoon and led to peers creating opportunities for each other. In addition to the conversations on the selected topic I feel it is important to acknowledge the comradery and support experienced by SHINDIG attendees. Highlighted in the comments below.

“Its good to be all on the same team, feels more like a family”.

“Simple things never change with Dementia; you don't forget how to love something like a hug could be so important”.

“Anyone who gets diagnosed with Dementia should talk to you two who are proof that there's life with Dementia”.

For more information about join dementia research please see:

[www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)

if you would like to get involved in research and prefer to do so in person, please let me know.

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For past reports go to [www.shsc.nhs.uk/shindig](http://www.shsc.nhs.uk/shindig)

Telephone number: 07811041412

**Next SHINDIG will take place on April 25<sup>th</sup> From 1pm-3:30pm at Ponds Forge**

**Please add the following number to your phone or put it on your fridge.**

**Dementia Advice Service Sheffield : 0114 2502875**