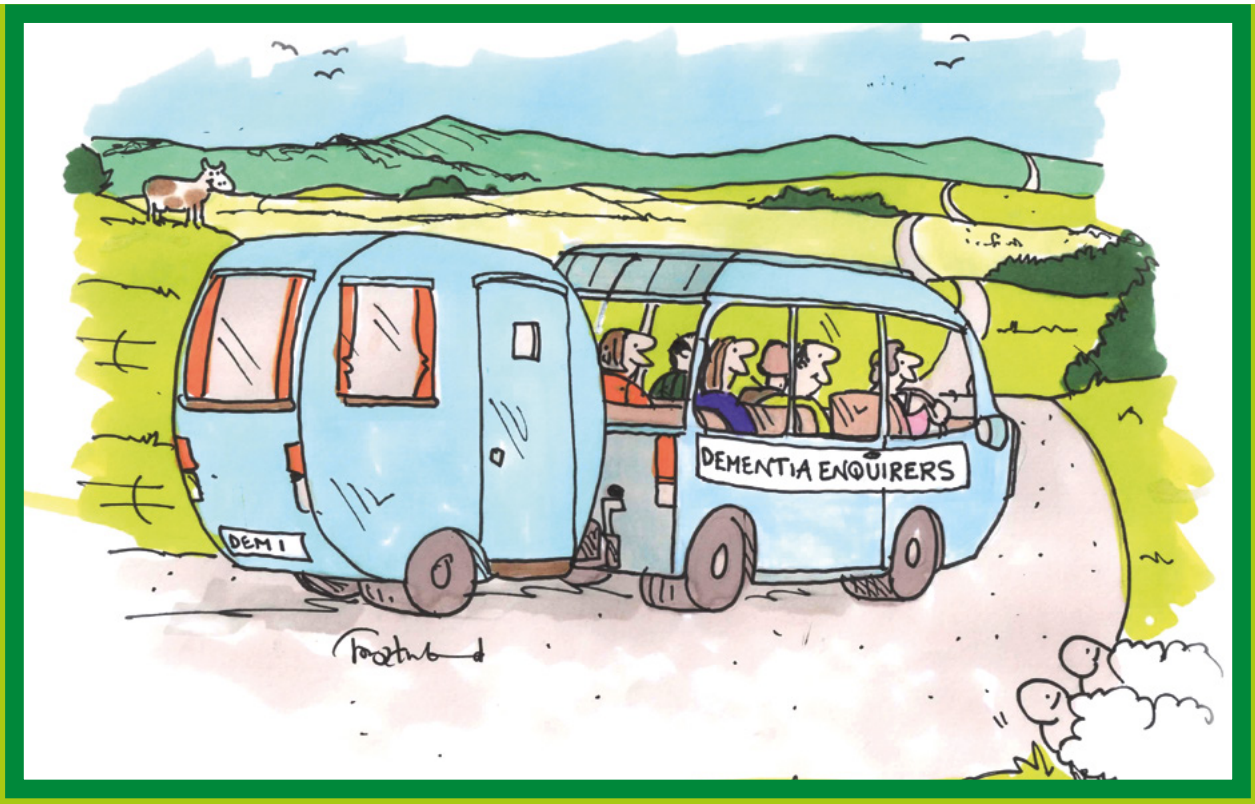
Shindig

Dementia Enquirers Report



To Drive or not to Drive with Dementia? That is the Question

August 2022

Dementia Enquirers

COMMUNITY FUND

Innovations in Dementia

Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.

2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.

3. "Being in the driving seat of research" doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.

4. Making the language and processes of research more accessible helps everyone!

5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

Date of publication August 2022

You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/shindig/

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To Drive or not to Drive with Dementia? That is the Question

This report specifically focuses on how this project was genuinely informed and 'driven' by a range of people living with dementia. The actual findings from the project are not shared in this report as they are being written up in a journal article [forthcoming] authored by members of the research group.

Introduction

Sheffield Dementia Involvement Group (SHINDIG) was formed in 2013 and is a forum where people living with dementia are supported to share their views, opinions and experiences of living with dementia in Sheffield. Meeting four times a year, each group focuses on a particular topic. However, whatever the topic, the issue of driving, or having to stop driving, is regularly raised in informal discussions amongst group members. This was also reported from local peer support groups. With this in mind the topic seemed the obvious choice to apply to the Dementia Enquirers research funding call.

This report details the different ways that people living with dementia informed and drove the research project throughout. The aim is to highlight the range of ways that individual people living with dementia contributed and to identify the ways that those people without dementia helped to practically administer the project. The report also discusses some of the challenges faced along the way, including the Covid-19 pandemic and associated restrictions which slowed the project down.

Background

The project idea

In many ways the project had already been chosen as an important topic to better understand by SHINDIG members and local peer support group, as the issue of driving, and more specifically having to stop driving, had been regularly discussed informally and within these meetings.

The Dementia Enquirers application was developed with three people living with dementia and there was great delight when it was found to have been successful. The success was announced and welcomed by the wider SHINDIG group.

Forming the research group and advisory group

SHINDIG members were approached and invited to join the research group. The five research group members had a range of experiences of driving, or not driving any longer, and different experiences of dementia. They also needed different levels of support to enable them to contribute.

Research Group Members: Experience, Skills and Roles

Member 1:

Was still driving but had made adaptations to driving to ensure safety. They actually made a plan during the research project with their spouse and consultant to ensure they would review regularly and stop if / when necessary.

This person took a lead role in undertaking the research interviews and focus groups, using the topic guides to ask the questions and facilitate the research conversations. This person also communicated with the research administrator, with gentle prompts which were welcomed and essential when the research faltered due to Covid-19 and recruitment difficulties. This person also reflected the sensitivities and sometimes judgements made of people living with dementia who were still driving. As the enduring member of the research group, this person contributed to analysis of the research data and to sharing the findings through presentations and written articles.

Member 2:

A former nurse lecturer who had decided to stop driving when their car needed repairs. This person made a choice to revoke their license and wanted to ensure no-one was put at risk by their driving.

The safety and integrity of the research was informed by this person's contributions. They were keen that the group had the correct ‘authority’ to undertake the research and their contribution resulted in the decision to obtain research ethics approval. This person contributed greatly to the research study information sheet and the interview topic guide.

Member 3:

A self-proclaimed ‘petrol head’ and business person who was still coming to terms with having been stopped from driving by their GP.

This person reflected on the importance of being prepared for the possibility of having to stop driving and was keen on understanding the policies and guidance that informed professional decisions. This person contributed to the questions that would be used in the interviews and to the participant information sheets, and also helped trial the topic guide questions in a ‘mock’ focus group role play.

Member 4:

A former police traffic officer who had a keen focus on the importance of road safety.

This person brought the legal aspects and safety issues of driving to the group. Sometimes this person told stories of the consequences of driving unsafely that were personally upsetting. This made the group think about how distress in focus groups or interviews would be handled. Sometimes this person was less able to explain things verbally but contributed greatly to the group decisions in gestures, actions and emotions. They made an important contribution to topic guide questions and to the research group generally.

Member 5:

A person who had been sent to have a driving test to assess whether they could continue to drive.

They shared their recollection of a seemingly unfair experience (of being sent to a test centre in a different city and expected to drive a very unfamiliar model of car). Although the person reported that they passed their test, the experience made them reflect and they voluntarily handed in their license.

This person brought compassion, spirituality, validation and positivity to all members of the research group. The person was a comfort to any distress amongst others and was a driving force to ensure fairness and integrity within the research process. Contributions were made by this person to the participant information sheets and interview topic guide questions. This person also contributed to the testing of the interview questions.

In order to support the work of the research group some people not known to have dementia contributed. These roles are described below.

Research Group Supporters: Skills, Experience and Roles	
Group Facilitator	A volunteer (without dementia) from SHINDIG offered to help facilitate the group sessions. This proved important in ensuring that the views and opinions of all group members were given the necessary attention. This person was able to help notice and interpret through the stories told and through non-verbal contributions made within the group.
Group Administrator	The organiser of SHINDIG (who also worked as a nurse and a lecturer at the University) took on the role of co-ordinating meetings, communicating with group members, arranging transport and refreshment and providing the administrative support in terms of taking notes from each meeting and bringing any necessary papers / resources to each meeting.
Various visitors	Up to four volunteers joined the group - one person interested in the topic, two students on placement, and an additional nurse volunteer wanting to gain research experience.

In addition to the research group, who worked on the ‘nuts and bolts’ of the research design, a research advisory group was formed to provide help and oversee the progress of the project. This group comprised a person living with dementia (who was also a Dementia Enquirers Pioneer), a family carer of a person living with dementia, a member of the local Alzheimer’s Society, a DEEP staff member and a member of staff from the University, whose particular role was to offer advice on the research design and ethics.

Some members of the research and advisory groups

The Development of the Research

Research Group Meeting Work in Designing the Research

Between August 2019 and February 2020 six face to face meetings were held to plan the research. The advisory group joined on two occasions.

All meetings were held in a City Centre venue familiar to group members. The staff in this venue were welcoming and helpful, providing a cuppa if anyone arrived early. This had the advantage of allowing some family members to accompany their relatives to the venue and

then have the opportunity to go shopping or meet friends for a coffee. If people needed a taxi to attend, this was arranged.

Refreshments were provided on arrival and a sandwich lunch was provide. These helped people to relax and also offered a social aspect to the meetings which enabled the group to get to know one another better.

Each meeting was started with a recap and reminder of the work already achieved, along with an agenda written on a flip chart. The Dementia Enquirers research guide offered a helpful structure around which to build understanding and confidence within the group about the research planning process. Each meeting was followed up with notes from the meeting in bullet format, see below:

- We decided to call our project "To Drive or Not to Drive: That is the Question"
- We looked at some guidance about driving from: 1: The Alzheimer's Society – guidance for people with dementia, family and friends; 2: A personal account from James McKillop who has dementia; 3: Some guidance aimed at professionals from the Royal College of Psychiatrists. Some group members took some of this away to look at out of interest.

- We discussed how when we do the research we will need to talk about this topic to other people with dementia. We discussed:
    - How we will need to listen to what others say and try and say less about our own experiences – this will not always be easy
    - The importance of having a 'moral code' when thinking about driving with dementia. We also need to respect the views of other people even if they are different to our own experiences and moral codes.
    - There might be strong feeling shared.

Excerpt of notes from a meeting

At the end of each meeting all group members were asked how they were feeling about the meeting. Responses from the first meeting included:

> “Scared and nervous about the process”
>
> “Worried about safeguarding – but feeling more reassured and that there will be support”
>
> “Non-committal”
>
> “Good”
>
> “Trepidatious” (new word made up)
>
> “Excited”

As meetings progressed, responses became more confident and reflected a pleasure in the work of the group. Comments included:

> “More comfortable about sharing my views”
>
> “It’s encouraging what we are doing”
>
> “Thoroughly enjoyed it – it’s gone brilliantly and we have all got our own vibe and way of going o.”
>
> “What we’ve done has been brilliant – but we must not rest on our laurels – we need to keep going”
>
> “Confident that we have the proper back up and we have some nice people involved and that we have the nice bits to do”
>
> “Driving a car is one of the most dangerous things we can do – we all have a moral duy.”
>
> “Feel pleased to be part of the gang and how well we are all working together”
>
> “We are a team – I appreciate tha.”
>
> “As long as there are biscuits!”

Key Topics and Decisions from Each Meeting		
Meeting 1: 13th August 2019	**Meeting 2: 21st October 2019**	**Meeting 3: 31st October 2019**
Getting to know one another and the topic. Understanding the project funding. Talking about ways to find out experiences of driving from people living with dementia, stories, interviews, discussion groups.	Starting to talk about a 'moral code' for the research group and for the research; recognising that different opinions about driving can raise different emotions in people. Group started to generate questions to ask in interviews and discussion groups.	The practicalities of doing the research. Joined by a University colleague. Talked about 'authority' to do this work and how to explain it to others. Awareness that people might talk about things that were 'illegal' or put others at risk. Group decision to get University Research Ethics approval and sponsorship. The need to have information to share with people who may want to take part in the research.

Key Topics and Decisions from Each Meeting		
Meeting 4: 21st November 2019	**Meeting 5: 30th January 2020**	**Meeting 6: 27th February 2020**
Reviewed / advised on information sheets that the administrator had started. Feedback from questions asked of DEEP and Zoom visit by DEEP. Information on advisory group purpose and members.	Report that the ethics application had been submitted - group pride at the materials. Decisions on refining the way interviews / discussion groups were run - so as not to have people still driving and people not driving in the same group - after feedback from group member. Joined by advisory group.	Reported that ethics approval was granted. Group members practiced asking questions. Dates agreed for conducting interviews. Students had reviewed current research and reassured us that our research is exploring something new and unique.
COVID-19 and associated restrictions arrived		

Research Ethics Approval

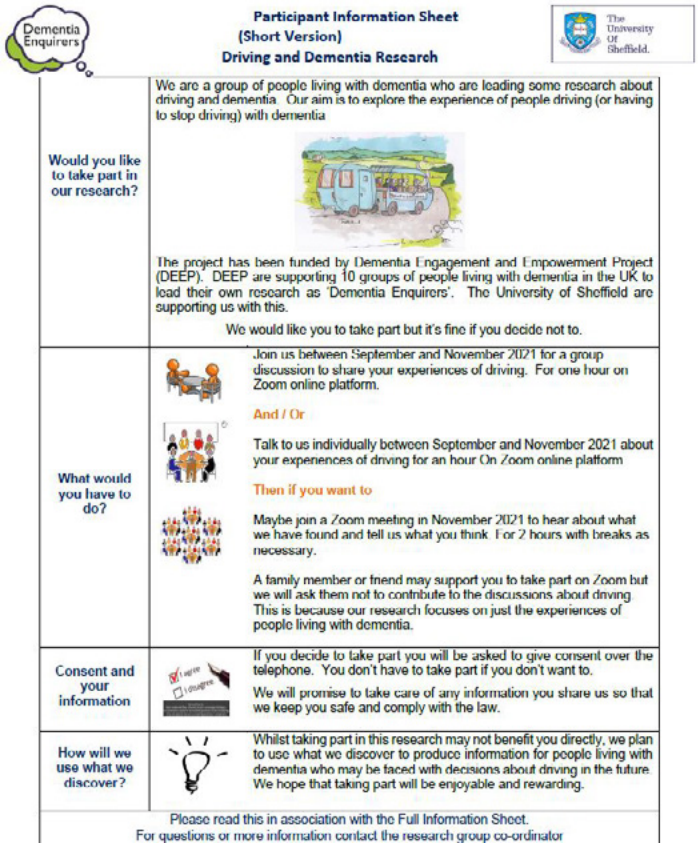
Group members spoke in different ways of the importance of the research having a 'moral code'. Members felt they needed the right 'authority' to ask others about their driving; had concerns over 'legal / illegal' admissions about driving, and wanted the research to make a difference to other people living with dementia and family members, as well as being taken seriously by healthcare professionals. Additionally, two of the group members / supporters (not known to have dementia) had professional codes of practice they needed to follow in order to take part in research. However, this was not the primary reason for seeking ethics approval.

A collective decision was made to take the research proposal through the University of Sheffield Research Ethics procedure. This required the group to develop a set of information for ethics committee members to review. This included:

- a research plan - saying clearly what was going to happen, when and how;
- a declaration of possible ethical issues and how these would be overcome;
- information sheets to help people decide whether or not they want to take part;
- consent forms to ensure people who took part were fully informed.

The development of these materials was delegated to the group member with administrative duties and the University staff member of the team. However, the group made decisions on what was included and what wasn't (within what was possible, as the ethics committee have certain requirements).

The ethics committee requires researchers to provide an in-depth information sheet that has particular information, including legal wording regarding data protection. The group felt that some people would want to understand and read an in-depth sheet, but they also wanted a shorter and more visual information sheet to accompany it.



Participant Information Sheet
(Short Version)
Driving and Dementia Research

Dementia Enquirers

The University Of Sheffield.

Would you like to take part in our research?

We are a group of people living with dementia who are leading some research about driving and dementia. Our aim is to explore the experience of people driving (or having to stop driving) with dementia

The project has been funded by Dementia Engagement and Empowerment Project (DEEP). DEEP are supporting 10 groups of people living with dementia in the UK to lead their own research as 'Dementia Enquirers'. The University of Sheffield are supporting us with this.

We would like you to take part but it's fine if you decide not to.

What would you have to do?

Join us between September and November 2021 for a group discussion to share your experiences of driving. For one hour on Zoom online platform.

And / Or

Talk to us individually between September and November 2021 about your experiences of driving for an hour On Zoom online platform

Then if you want to

Maybe join a Zoom meeting in November 2021 to hear about what we have found and tell us what you think. For 2 hours with breaks as necessary.

A family member or friend may support you to take part on Zoom but we will ask them not to contribute to the discussions about driving. This is because our research focuses on just the experiences of people living with dementia.

Consent and your information

If you decide to take part you will be asked to give consent over the telephone. You don't have to take part if you don't want to.

We will promise to take care of any information you share us so that we keep you safe and comply with the law.

How will we use what we discover?

Whilst taking part in this research may not benefit you directly, we plan to use what we discover to produce information for people living with dementia who may be faced with decisions about driving in the future. We hope that taking part will be enjoyable and rewarding.

Please read this in association with the Full Information Sheet.
For questions or more information contact the research group co-ordinator

Summary participant information sheet

There were concerns by people outside of the research group that the ethics process would be lengthy and not necessary. However, it was important to group members to feel comfortable in taking the research forward. Group members voiced pride in the materials that were produced. Here are some of the comments from research group members specific to the ethics approval:

> "It was good that we had some help (from the University) whilst we could still get the kudos!"
>
> "Fine – it's gone wonderful – amazed no-one collapsed in the middle (the amount of work we got through) – smashing."
>
> "The fact we have gone through ethics gives us a better starting point."
>
> "It might have all been ad hoc if we had not got everything organised."
>
> "It will give us more credibility."

Having ethical approval also ensured that, if the group wanted to write about the research to include people who make policies, or professionals who make decisions about whether people should continue to drive or not, it would be taken more seriously if ethical considerations had been formally assessed.

The impact of Covid 19 on the momentum of the project

Before Covid-19 arrived, the group had achieved great momentum and the research was ready to start. The group were at the point of finding people to take part in the research and share their experiences. Group members had practiced asking questions and were confident in their authority and ability to undertake the research.

Sadly, the momentum and the ability of the group to meet was restricted early into the pandemic and confidence in using online methods of meeting was initially quite low.Completing the interviews or discussions groups face to face was no longer an option. The staff and volunteers supporting the project were pulled in different directions, either personally or in relation to work. So twelve months passed with occasional updates to the research group. An ethics amendment had given approval for the research interviews and discussion groups to take place online.

Twelve months after the pause the group reconvened on Zoom. Confidence in using Zoom had increased and there was an appetite from all to continue. However, one of the group members had spent time in hospital and was now in a care home, another member had lost contact, and the volunteer facilitator had withdrawn for personal reasons. This left the group depleted but still resolute.

Plans were made to start recruiting to the study and a discussion was held with two group members to gather their experiences of still driving or having to stop driving. Consent was gained to use this as research data. The advisory group gave suggestions on where to share the research information to find people to take part.

Recruitment to the study

The advisory group suggested we visit some of the online forums. A group member and the group administrator visited a number of online cafes, groups and key worker events. Finding people to take part in the study proved a challenge for a number of reasons:

a: Previously it had been easy to chat directly to people living with dementia at cafes and groups taking place in the City, but these had been moved online. SHINDIG had also moved online and some of the people who had regularly attended had chosen not to access the group online.

b: Some members of the research team visited online forums to invite people living with dementia to take part in the study. Many of these seemed to focus more on family carers. Also some people with dementia who attended may have found it difficult to recall the date when they had to stop driving. Workers said they thought carers' views on stopping driving were important, which of course they were - but that was not the focus of the research that the research group had decided upon.

Eventually it was decided to use social media to try and find people more widely across Yorkshire to take part in the study. Twitter was used and key people from the advisory group and from DEEP helped to distribute the message. This included an online form that people could complete and then the administrator made contact. This was not without difficulties:

a: Sometimes people did not include contact information, or completed the form but then did not respond when contacted.

b: One person with dementia showed an interest but relied on their spouse to support them and the spouse felt it was not the right time for the person to take part. This reflected the extra challenges that not meeting people face to face brought to the project and how 'gatekeepers' sometimes prevented access.

Finally, two years after the start of the project, interviews and discussion groups started. In total nine people living with dementia shared their experience of driving or not driving through three focus groups and three interviews. Seven people had stopped driving and two people continued to drive. Findings from this are currently being written into a journal article. When published this will be made available on the Dementia Enquirers website **here**.

Reflections on people living with dementia 'driving' the research

1: Developing group unity

As not everyone in the research group knew one another, establishing group confidence and unity was essential. This was achieved through taking time initially to help the group feel relaxed and get to know one another. It was important to listen to the concerns of group members and help reassure and build confidence in the group. One group member, who was still driving, initially felt uncomfortable talking about still driving in a group where people largely had the view that it was not always safe for people to drive. As the group got better acquainted, ground rules were agreed that it was OK and indeed important to have different views, opinions and experiences. The group member who still drove then had an important influence on how the interviews and focus groups were organised.

2: Including people with a range of ways of communicating

Our research group aimed to be inclusive of any person living with dementia who had an interest in the topic of driving and the research project. Initially seven people showed an interest in joining the group. Two people subsequently chose to not take part in the main research group. One person declared a conflict of interest, being a Dementia Pioneer who had helped to select the Dementia Enquirers projects (although they had taken no part in the selection of this particular project). This person became a valuable member of the research advisory group and had an important role in helping to advertise the research through social media channels. Another person was also going

through the process of having to give up their driving license, and found themself becoming angry and emotional within the group. Whilst offered support to continue, the person decided it was not helpful to his current situation and did not remain part of the group.

One group member in particular may easily have been excluded from taking part in the research group. The person found communicating difficult at times and their spouse was concerned about how much the person was contributing. As with all group members, this person's contribution was immense and valued by all concerned. Emotional stories that were told were listened to and supported by the group. The group facilitator helped to articulate and include the gestures and non-verbal communication made. The person's spouse remarked upon the positive mood of the group member some hours after the meeting had ended.

People chose how they preferred to contribute to the group. Some members were happy to take a lead on the interviews and focus groups, whilst others preferred to take away written materials to read and comment on outside of the meeting. One member was an immense positive influence on the group and was quick to offer compassion and support. Another member noticed if a group member needed practical help and offered this.

3: The contribution of the research group to 'doing' the research

Due to the length of time taken to begin the research interviews, just one of the original five group members was available to remain involved in the study. This person remained central in prompting the administrator to maintain momentum, and in asking the questions in the research interviews and focus groups. Once the data collection was complete and the interviews and focus groups were typed up, this group member - along with the administrator and University staff member - met up to organise what had been said in the research into 'themes'. The group member voiced some concern at being able to process this way of working. The meeting was adapted to a conversation about what people had said and the University staff member made notes. These notes were presented back in a logical process of what happens when people with

dementia start to have to think about driving or not driving. The group member felt that made sense and had felt included within the analysis process. This member preferred not to write the research reports and research paper - delegating this to the administrator. This group member and advisory group member contributed greatly to the editing and format of the report.

4: The contribution of supporters not known to have dementia

The staff member taking on the co-ordinating / administrative role tried to remain self-aware and questioning of their role and whether they might be influencing the research group. These conversations were had in an open and honest way with group members and these accounts were recorded in the meeting notes. No group member wanted to take on administrative tasks and keep other group contact details and make arrangements, so this was delegated to the staff member. We discussed how academic advice could be best used by the research group. This was likened to calling in a specialist. For example, if we need our car servicing, most people tend to take it to a mechanic who has the skills and knowledge to undertake the service safely and efficiently and offer advice on any problems. People in the group were the experts on living with dementia or cognitive difficulties, their knowledge of what was important to themselves and others in relation to driving or not driving. They also brought diverse skills and experiences of life, interpersonal skills, attention to detail, knowledge of legal aspects of driving and research, their values and humanness.

Summary

This important research topic evolved from conversations between people living with dementia over a number of years. The Dementia Enquirers funding provided the opportunity for people living with dementia to design and run a number of focus groups and interviews to better understand the experience of driving, or having to stop driving, from the perspectives of people living with dementia.

This report details the range of skills, life experiences and personalities of the research group members and the ways that these influenced how the research was planned. A strong emphasis on safety, authority and moral codes resulted in the research seeking formal ethical approval and University research authority. This offered reassurance to the group and also ensured the research could be shared in the knowledge it had been undertaken in line with accepted research standards and principles.

The Covid-19 pandemic interrupted the research, and plans were changed to ensure the research continued using online interviews and focus groups. This had consequences for reaching the number of people originally planned. However in-depth conversations with nine people living with dementia has provided important insights into the experience of continuing to drive or having to stop driving for people living with dementia. These findings are being written for a dementia research journal and will be shared in the future when the account is published.

This project demonstrates that, given the right support, people living with dementia can truly drive and deliver research that is important to their own lives.

Acknowledgements

This report was informed by the work of the research group who agree to be named, and included:

Martin Cooper

Peter Terry

Barrie Richmond

Ken Cole

Margaret Johnson (pseudonym)

The report was written by Jane McKeown and validated by Martin Cooper (research group member) and Howard Gordon (advisory group member and Dementia Enquirers Pioneer)

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