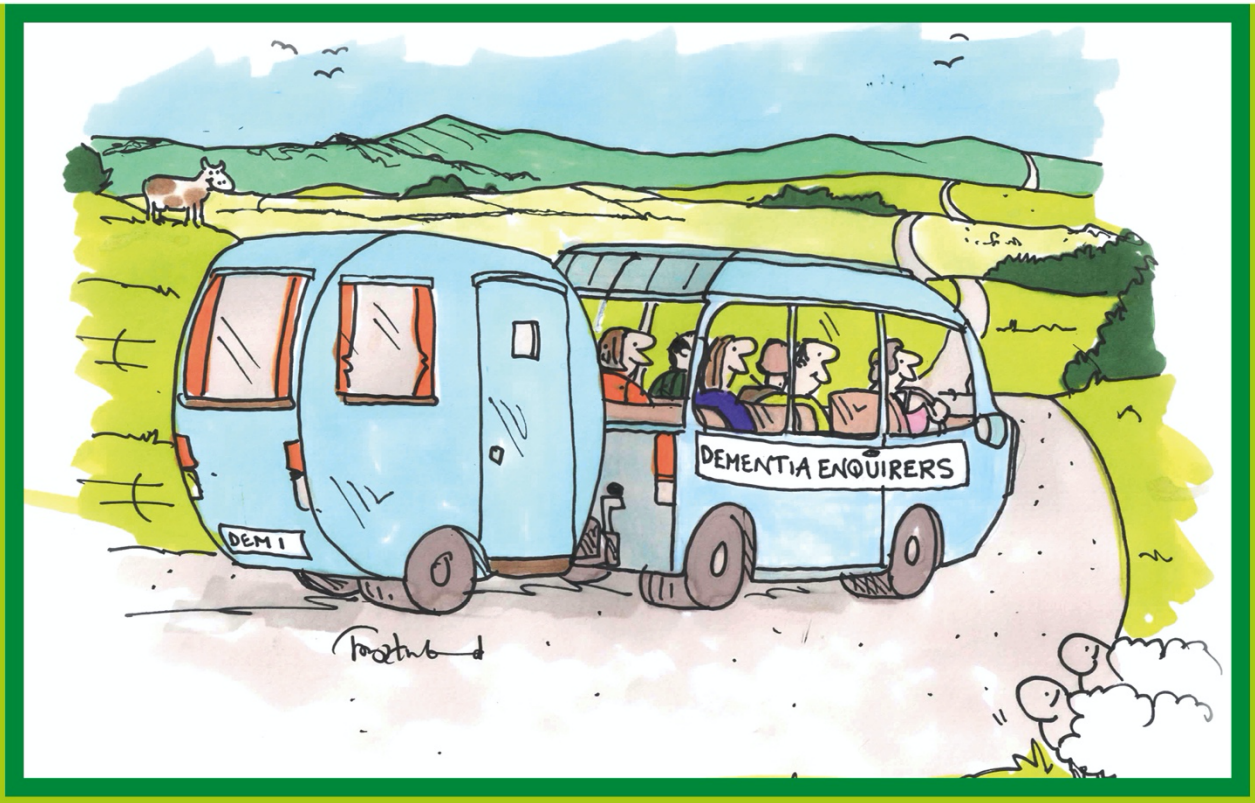
Shrewsbury Riversiders – York Minds and Voices

Dementia Enquirers Report



DEEP/Admiral Nurse enquiry

2019-2021

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 May 2021

You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/riverside-in-shrewsbury-with-minds-and-voices-in-york

You can read other Dementia Enquirers reports here:
https://dementiaenquirers.org.uk/individual-projects/

To find out more about Dementia Enquirers visit:
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Contents

Short Report and Recommendations....4
How many Admiral Nurses know about and meet DEEP groups? 4
Summary Findings 5
Conclusions 6
Recommendations from the survey findings....7
Actions agreed with Dementia UK in discussion of the findings 8
Full Report 9
Key Findings 9
About the research project....11
The process 13
Getting the questionnaires out there....14
Detailed Findings 15
Admiral Nurse Survey....15
Conclusions from Admiral Nurse Responses 20
Benefits of Meeting DEEP Groups....22
Themes for Learning from the Survey 23
Survey of members of DEEP groups....25
Conclusions from DEEP member questionnaires....29
People with dementia in the driving seat – learning points....30

To find out:

a) **how many Admiral Nurses know about and meet DEEP groups**

b) **how many DEEP group members know of and have access to Admiral Nurses**

Short Report and Recommendations

The questions:

How many Admiral Nurses know about and meet DEEP groups?
How many DEEP group members know of and have access to Admiral Nurses?

How it came about:

George Rook and Damian Murphy wondered if there was much interaction between DEEP groups and Admiral Nurse services and what potential there might be.

What we did:

Eddy, Paul and Stewart (York Minds and Voices) went to Stockport with Damian to meet with George, David and Dawn (from Shrewsbury Riversiders). If it wasn't for Eddy we'd still be driving round the Manchester ring road!
We agreed the wording and punctuation of the questionnaires that went out to DEEP groups and to Admiral Nurses.

Summary Findings

Admiral Nurses

- 82 Admiral Nurses completed the questionnaire. Most had heard of DEEP but not all sure of what it is
- 87% said it would be beneficial to have contact with a DEEP group
- Only 8% had any contact with DEEP groups

Admiral Nurses saw the benefit of contact with DEEP groups in three broad areas

- learning directly from people living with dementia
- helping them in their information giving
- and promoting Admiral Nurse services and carer support

DEEP group members

- 41 DEEP member questionnaires were returned from across 10 DEEP groups. Two thirds were from people living with dementia
- Half said they had heard of Admiral Nurses, though only 17% said they knew what Admiral Nurses do

Upon seeing information about Admiral Nurses

- 76% said they would find an Admiral Nurse helpful now

DEEP groups could see the benefits of Admiral Nurse contact

- to provide support, knowledge and information
- because there is little or no support in the area
- because existing support is voluntary

Conclusions

There is clearly much enthusiasm for Admiral Nurses to meet their local DEEP groups. However, very few Admiral Nurses have actually made contact, so there is work to be done if we want this to happen.

Admiral Nurses recognise that there would be benefits for their work in meeting DEEP groups.

Likewise, a majority of respondents from DEEP groups could see the benefit of having Admiral Nurse support after seeing the explanatory information about them. However, that contact is currently limited.

We have found out that there is little work or contact going on between Admiral Nurses and DEEP groups. Just as Admiral Nurses are missing out on considerable learning, so DEEP members miss the opportunity to learn about Admiral Nurses, and to get their advice and experience to help them live as well as they can.

Our overall conclusion is that Admiral Nurses believe that they would benefit in their work from meeting DEEP groups where they exist, and that both DEEP and Dementia UK should work to facilitate this happening.

Recommendations from the survey findings

1. That Admiral Nurses be informed about what DEEP groups are, and where they exist

2. That Admiral Nurses are encouraged, and given time, to meet any local DEEP group on a regular, though not necessarily frequent, basis

3. That Helpline staff are similarly encouraged to make contact with a DEEP group and establish a relationship with it

4. That DEEP groups be contacted by Dementia UK to provide support to influence locally for Admiral Nurse services in their area

5. That the Trustees of Dementia UK are made aware of this research so they understand the demonstrated need and enthusiasm for more Admiral Nurses services, and the need to publicise and communicate about Admiral Nurses and the Helpline

6. That Dementia UK establishes a relationship with Innovations in Dementia to promote and publicise the importance of, and existence of, Admiral Nurse services

7. That the DEEP network as a whole should work to build relationships with Admiral Nurses

Actions agreed with Dementia UK in discussion of the findings

Virtual meeting of:

Damian Murphy, York Minds and Voices Facilitator
George Rook, Shrewsbury Riversiders Facilitator and member
Paul Edwards, Director of Clinical Services, Dementia UK
Gill Maidens, Consultant Admiral Nurse, Dementia UK

The following actions were agreed, in order to implement the recommendations of the report.

1. Produce and use for training a film about the DEEP network

2. Produce an overlay map of Admiral Nurse and DEEP group locations

3. Advise Admiral Nurses to use the resources on the Dementia Voices website, such as DEEP guides and Dementia Diaries

4. Add information about LEAP (Lived Experience Advisory Panel) to the Dementia UK Learning Academy (Blackboard)

5. Promote the fostering of relationships between DEEP groups and Admiral Nurses

Full Report

Key findings

Admiral Nurses

82 Admiral Nurses completed the questionnaire.

94% had heard of DEEP groups, though 10% were unsure what they were.

28% said they did know of a DEEP group in their area.

8% of all respondents said they had had contact with a local DEEP group.

87% said they thought meeting a DEEP group would be helpful in their work.

DEEP group members

41 DEEP member questionnaires were returned. Two thirds were from people living with dementia, one third from unpaid carers.

Of people living with dementia, 42% were diagnosed under the age of 66.

Responses were received from members of 10 DEEP groups.

Half of respondents said they had heard of Admiral Nurses, though only 17% said they knew what Admiral Nurses do.

Just 1 respondent stated that there was an Admiral Nurse in their area.

76% said they would find an Admiral Nurse helpful now, and a further 20% said they would want one in the future as the disease progressed.

The main reason given for saying they wanted an Admiral Nurse was current lack of support for people living with dementia and unpaid carers.

While 27% said they had been involved in influencing with a CCG or NHS Trust, 85% said they would want to in the future, now they know more about Admiral Nurses.

About the research project

In 2019 George Rook (Shrewsbury Riversiders) and Damian Murphy (York Minds and Voices) met at a regular meeting of the Dementia UK LEAP group (Lived Experience Advisory Panel). Dementia UK is the charity that promotes, trains and supports Admiral Nurses.

Admiral Nurses provide specialised support for people affected by dementia, often, but not always family groups when they face particular challenges. Admiral Nurses, of whom there are currently some 300, are usually employed by a host organisation, such as a primary care trust, a charity or a care provider. A growing number are employed in hospices, and a few work in hospitals.

George and Damian discussed how DEEP (Dementia Engagement and Empowerment Project) groups and Admiral Nurses interacted, if at all. They also recognised that many areas of the UK do not have access to Admiral Nurse services, and that many people affected by dementia may not have heard of Admiral Nurses.

They agreed to develop a bid to Innovations in Dementia, specifically to the Dementia Enquirers Project, to carry out research to answer these questions. The research would make people around the UK more aware of the existence and role of Admiral Nurses and would provide Dementia UK with valuable learning that would enable them to develop their strategy and services.

Dementia Enquirers, funded by The National Lottery Community Fund, promotes the design and execution of research into issues affecting people living with dementia. Requirements include that people living with dementia must be ‘in the driving seat’ of the project. It must be their ideas and their work, as far as possible, with assistance as necessary from others, including research professionals.

Other requirements include that findings must be reported to those who took part, and to the wider dementia community, and that the methods used must be dementia friendly and accessible.

Research topics must be chosen by members of DEEP groups, i.e. people living with dementia, but there is almost no limit to what a topic might be, as long as it affects members of that or those DEEP groups. Many topics have wider application, of course.

The process

In early 2019 George designed an initial project brief and shared it with Damian. It was shared with both Riversiders and Minds & Voices, and both groups agreed to submit the bid.

In the summer the Dementia Enquirers bid was approved by the Dementia Pioneers group of people living with dementia steering the project.

George designed and drafted two questionnaires, one for people living with dementia members of DEEP groups around the UK, and one for Admiral Nurses. These were then shared with both DEEP groups, and with Dementia UK, for comments and suggestions.

A second draft was created, and three people from Riversiders met four from Minds & Voices in Stockport (a convenient halfway point on the train) to work through and test the questionnaires. We hired a room at a local community facility.

Several changes were agreed and a final draft of each questionnaire was written and sent for approval to Minds & Voices, Riversiders and Dementia UK.

Getting the questionnaires out there

In November 2019 Innovations in Dementia printed, collated and distributed the DEEP questionnaires to groups. Comprehensive instructions were included, and groups were urged, through facilitators, to discuss the questions as they worked through them, to ensure that members understood. But we specifically asked for individual responses, not group agreed answers. There was also an envelope for each group which contained a short description of what Admiral Nurses do, which had been provided by Dementia UK.

The envelope was to be opened halfway through the questionnaire, so that the later questions could be answered.

The Admiral Nurse questionnaire was put onto Survey Monkey, and all Admiral Nurses were sent a link to it and encouraged to complete it. It was estimated that it would take no more than five minutes to complete.

As most DEEP groups meet once a month, we expected to give around three months for groups to complete the questionnaires. A few did this in January and February, but then COVID came and stopped all meetings. Thus, 42 questionnaires were completed and returned, from nine groups.

However, many Admiral Nurses completed their online questionnaires during their monthly training and support meetings, and eighty-two were completed.

Since no face-to-face meetings have been possible, George undertook that analysis and interpretation of the questionnaires in February 2021. The findings are detailed below.

Detailed Findings

Admiral Nurse Survey

82 online Survey Monkey questionnaires were completed. Each took an average of around 3 minutes.

Question 1

Are you an Admiral Nurse?

Yes 82

No 0

Question 2

Which area of the country (county or city/town) do you work in?

The following counties/cities/towns were covered...

London
Cheshire
Kent
Kirklees
Norfolk
North East
East Kent
Telford
West Midlands
Swindon
Honiton
Cirencester
Essex
Hertfordshire
Leicestershire
West Yorkshire

Warwickshire
Norwich
Northamptonshire
Hampshire
Coventry & Warwickshire
Staffordshire/Manchester/Cheshire
Durham
East Sussex
Rutland
Denbighshire
Merseyside
Kent
Oxfordshire
Bristol
East Anglia
Lincolnshire
Southampton
Cardiff
Devon
South West
Black Country
Suffolk
Somerset
Leicestershire
West Sussex
Wakefield
Manchester
Isle of Man
Tameside

Question 3

What type of service do you work in?

Secondary community	22
Primary community	18
National helpline	11
Hospital(s)	9
Hospice	9
Charity provider	5
Care or nursing home	3
Admiral Nurse Consultant	3
Local council	1
General Practice	1

Question 4

Have you heard of DEEP groups?

Yes 69 (84%)
Yes 8 (10%) (but unsure what they are)
No 5 (6%)

Question 5

Do you know if there is a DEEP group in your area?

Yes 23 (28%)
No 59 (72%)

Question 6

If there is a DEEP group nearby, please tell us its name or town.

23 positive responses, covering:
East Kent Forget Me Nots
Kirklees DEEP, West Yorkshire
North Shields
Shropshire
Wellington (wrong group: none at Wellington/Telford)
SURF, Liverpool
Leamington Spa, Warwickshire
Crewe, Cheshire
Brighton
Brent Voices, London
Ruddlhan, Denbighshire
Northfleet, Kent
Swale, Kent
Sutton, London
Making Waves, Tyneside
Fabulous Forgetful Friends, Manchester

Question 7

If you have had any contact with a DEEP group please explain what this is.

6 (8%) Admiral Nurses reported having had contact with a DEEP group:

'Worked with DEEP group on post diagnosis pathway'
'With the group leader'
'Every few months I meet two members who volunteer with me'
'Attended meeting'
'Shared contacts and local information'

Question 8

Do you think it would be beneficial for you to meet members of a DEEP group?

Yes	71 (87%)
Unsure	7 (8%)
No	1 (1%)
No answer	3 (4%)

Question 9

What do you think might be the benefits for you in your work of meeting with members of a DEEP group?

Responses were coded according to the following descriptions. Note that many responses covered more than one coding.

a) Learn first hand lived experience of people living with demnetia 23
b) Collaboration and/or networking 15
c) Learn about local support services 13
d) Help to tailor/design Admiral Nurse services 12
e) Refer onwards or signpost 11
f) Learn about DEEP groups 11
g) Support people living with dementia 10
h) Understand needs of people living with dementia and carers 7
i) Support carers 6
k) Help me in my Helpline work 6
l) Understand the challenges of people living with dementia 5
m) Increase awareness of Admiral Nurses (ANs) 5
n) Learn what does/doesn't work 5
o) Understand support needs in hospital 2
p) Learn about carers' experiences 1
q) Other 5
r) Unsure 1

Conclusions from Admiral Nurse Responses

Coverage

82 Admiral Nurses responded

79 (96%) are based across England
2 (3%) work in Wales
1 (1%) works in the Isle of Man

England was well represented geographically, but there were no responses from Scotland or Northern Ireland based Admiral Nurses, and only two from Wales. This probably reflects the location of Admiral Nurse services.

Types of services

40 out of 82 (49%) responses were from Admiral Nurses working in the community, either described as Primary or Secondary services.

Only 1 Admiral Nurse recorded that they worked in General Practice.

9 (11%) Admiral Nurses worked in each of Hospices and Hospitals.

11 (13%) Admiral Nurses work on the National Helpline.

Awareness of DEEP Groups

69 (84%) Admiral Nurses reported that they knew what a DEEP group is.

8 (10%) said they thought they did but were unsure.

5 (6%) said they had not heard of DEEP groups.

23 (28%) Admiral Nurses recorded that they knew about a DEEP group in their area.

6 (7%) Admiral Nurses reported having had contact with a DEEP group.

Benefits of Meeting DEEP Groups

These are listed above, and the actual comments are recorded verbatim in the appendix.

A small number of responses referred to hearing from or supporting carers. This may imply that some Admiral Nurses think DEEP groups are for carers, or both carers and people living with dementia. Most groups, however, (and this was stated in the explanations in the questionnaire), comprise people living with dementia only.

The majority of responses referred to learning and understanding about the lived experiences of, and challenges faced by, people living with dementia.

24 (29%) referred to help in designing Admiral Nurse services, learning what works and what does not, and what people's actual needs and wants were.

15 (18%) responses referred to collaboration and networking.

13 (16%) responses indicated that the Admiral Nurse would use the DEEP group to learn about local support services.

11 (13%) responses referred to signposting members to services, or indeed signposting people living with dementia to the DEEP groups.

11 (13%) said they wanted to learn about DEEP groups by meeting them.

5 (6%) said they wanted to increase awareness of what Admiral Nurses do.

Themes for Learning from the Survey

Most Admiral Nurses have heard of DEEP groups, though several were unsure what they were. Only 28% stated they knew of a DEEP group in their area. Some who answered ‘no’ (72%) may have meant either that there was no group, or that they did not know of a group.

There is clearly much enthusiasm for Admiral Nurses to meet their local DEEP groups, to learn from them and to work with them to tailor their services and support.

However, very few Admiral Nurses have actually made contact, so there is work to be done if we want this to happen.

Admiral Nurses recognise that there would be benefits for their work in meeting DEEP groups, including shaping services to accord with lived experience and actual stated needs.

Helpline staff frequently stated that meeting DEEP group members would help them with their work with callers. This may be an area for further work, as there were no contacts reported.

Our overall conclusion is that Admiral Nurses believe that they would benefit in their work from meeting DEEP groups where they exist, and that Dementia UK should work to facilitate this happening. It is notable that one comment stated that there is not enough time, and we might venture that this would be true of many or most Admiral Nurses. But the benefits, as revealed here, might be regarded as outweighing the time involved, a few hours a month in most cases.

We have found out that there is little work or contact going on between Admiral Nurses and DEEP groups, and that Admiral Nurses are therefore

missing out on considerable learning, while DEEP members miss the opportunity to learn about Admiral Nurses, and to get their advice and experience to help them live as well as they can.

Survey of members of DEEP groups

42 paper questionnaires were returned:

People living with dementia 26* (64%)
Unpaid carers 14 (34%)
Did Not Answer 1 (2%)

1 questionnaire contained answers that were contradictory and was therefore discarded.

Responses were submitted from 10 DEEP groups:

1	Buddies, Leamington Spa
3	Face it Together, Shipley/Bradford
5	Friends for Life, Nottingham
1	In at the Deep End, Nottingham
6	Kirkintilloch Dementia Voices
3	Mansfield and Ashfield Working Age Group
2	Scottish Alumni
4	Wizards of Os (Shropshire)
14	York Minds & Voices
2	Unspecified

*11 of 26 (42%) of people living with dementia had been diagnosed before age 66.

Question 1

Have you heard of Admiral Nurses?

Yes 20 (49%)
No 21 (51%)

Question 2

Do you know what Admiral Nurses do?

Yes 7 (17%)
No 18 (44%)
Unsure 16 (39%)

Question 3

Is there an Admiral Nurse in your area?

Yes 1 (2%)
No 21(51%)
Unsure 19 (47%)

Question 4

Have you ever been supported by an Admiral Nurse?

Yes 1 (2%)
No 40 (98%)

Question 5

Having read the description of an Admiral Nurse role, do you think an Admiral Nurse would be helpful?

Yes 31 (76%)
No 8 (20%)
Unsure 2 (4%)

Comments on "Would an Admiral Nurse be helpful"?

Coded as follows:

7 Don't need it currently/yet
6 Providing more support
5 Knowledge and information
4 Little or no support in this area
3 Current support is voluntary
3 Help claim benefits and/or plan future
3 Would be someone to help with shopping etc
1 Have used Dementia UK Helpline
1 I need Admiral Nurse help before crisis/late stages
0 Unsure

Question 6

Have you ever been involved in 'working' with CCG or Trust to improve services?

Yes 11 (27%)
No 30 (73%)

Question 7

Now you know about Admiral Nurses, would you consider trying to influence change?

Yes	35 (85%)
No	2 (5%)
Did not answer	4 (10%)

Any other comments?

Coded as follows:

10 No support here
4 Support is from voluntary organisations
2 I great comfort and support from my DEEP group
2 Have a dementia navigator, but they're too busy
2 Alzheimer's Society in Bradford is excellent
1 Not enough provision for under 65s
1 Need age appropriate help
1 Plenty of support for people living with dementia, not for carers
1 Need support for people with dementia to live independently
1 Having an advocate helps you fight your case

Conclusions from DEEP member questionnaires

The geographical spread of respondents was limited by the response rate, due to Covid preventing meetings. Groups that did respond covered broadly the northern half of England, with two groups from Scotland.

Two thirds of respondents were people living with dementia, one third unpaid carers. This reflects that DEEP groups are primarily attended by people living with dementia.

Half of respondents had heard of Admiral Nurses, but only 17% felt they knew what Admiral Nurses do.

Only one respondent said they knew of an Admiral Nurse in their area.

After reading about what Admiral Nurses do, 76% said an Admiral Nurse would be helpful. A further 18% stated they did not need an Admiral Nurse yet. Only one respondent was unsure.

Main reasons why an Admiral Nurse would be helpful were:

- to provide support, knowledge and information
- because there is little or no support in the area
- because existing support is voluntary

One respondent said they had used the Dementia UK Helpline.

In other comments the overall theme was that there was little or no support in the area.

There was praise for the value of support from being in a DEEP group, and for the activities provided by Alzheimers Society in Bradford area.

People with dementia in the driving seat – learning points

The key requirements of an Dementia Enquirers research project are:

- At least 3 people with dementia are named as research leaders
- The project is controlled by these named people with dementia 'in the driving seat'
- As much work as is realistic or possible to be carried out by people living with dementia
- The project should lead to learning that is useful and practical in relation to people living with dementia and/or DEEP

1 Whose idea was it anyway?

One person has an idea, talks about it with others, finds support, and then decides to write an application.

If someone knows and talks to a member of another group there can be cross fertilisation. Alternatively you specifically ask a group if they are interested.

Any idea can be batted around and shaped by discussion, but in the end successful projects or big ideas rarely stem from, or are managed by, committees. The focus required has to be applied, usually by one person, after getting consent and support from others.

Everyone has different experiences and skills. The trick is probably to find an issue to research, which encompasses a good number of group members' interests and experiences.

Admiral Nurses worked because once people know about them they always want one or more in their area. The same might apply to working with GPs; we all depend on them and use them.

2 Who does the work?

Who has the skills?

What skills do we need?

What equipment do we need, and can we use it?

These dictate who does the work.

In our case, several Riversiders have highly relevant and useful skills, although due to lockdown it was almost impossible to work together on the project. George led it, but discussed ideas and approaches with Riversiders via Zoom. While planning it, George worked out research approaches and questions and agreed these in outline with Damian. Then drafts were given to Riversiders, and three people responded with detailed suggestions.

Two Riversiders (plus one spouse) met two York Minds & Voices members plus Damian (their facilitator) in Stockport for half a day, lunch included, to test the surveys for wording, clarity and answerability. Changes were subsequently made by George.

Dementia UK were involved by George (through LEAP) at early stages and for consultation at various stages, to ensure they felt involved, and would therefore be committed to action following the project's findings.

The questions were tested out by George visiting a Birmingham CPD Admiral Nurse group.

Printing and posting of DEEP group surveys were kindly done by Innovations staff, saving a lot of hard, boring work! Do try to piggy back onto an existing service like this if it is appropriate and possible. All depends on your project.

I had an offer from a Riversider person with dementia to help with data collation, but without being able to meet it was easier for me to do it on my own. It took about two days to collate, sort, and draw conclusions, before writing the report.

I wrote the report, using ‘we’ throughout. I shared first draft with Damian and he suggested just one or two changes, but more importantly wrote a summary and recommendations page to go at the front.

The second draft was then shared with Dementia UK. Amonth later Damian and I met online with the Dementia UK Clinical Director and one of the LEAP facilitators/consultant Admiral Nurse. We agreed several actions that both sides committed to, and were incorporated onto the draft. The draft was also scrutinised by another person with dementia Riversider.

A final version was completed and sent to Innovations and Dementia UK, and later to members of LEAP, Riversiders and Damian (for York Minds &Voices).

3 Working together across two groups

Is challenging! If they are close, and you can meet, it will of course be relatively easy. At a distance, as we were, we managed to meet in person at a halfway place, Stockport. Damian drove his people down, and I and two Riversiders went up by train. I found on the web, and hired, a community space close to the station, and ordered in lunch from a recommended nearby shop.

Those who attended did a really good job of challenging what I thought were already pretty watertight survey questions! So I changed quite a lot of detail afterwards. It was also just a good day of chat and discussion. That was a powerful spin off, and without Covid we would have met again.

4 Doing the research data gathering

Designing your questions/surveys.

If your group happens not to include someone with the requisite skills (and willingness) to help with or devise the questions, find someone who does! Pay them if you have to, as this is the mission critical element of the research.

And this might apply to interview type research too. I can promise you that being interviewed by a researcher who doesn't know what they are doing is just plain bloody annoying and will put you off ever being involved again.

One particular word of caution. To do any sort of research, but even more so in a survey, you have to make the questions watertight. Any room for alternative interpretation or doubt has to be removed.

Secondly, think carefully about the sequence of questions. Don't give a later answer away by asking a question out of sequence.

Think about creative ways of getting the data you want, so you don't need to go back and ask again. We need to know what people living with dementia thought about Admiral Nurses, but we knew most people don't know about them. So we asked the questions about their knowledge and experience, and asked them, written into the instructions, to only then open an attached envelope with a description of what Admiral Nurses do. THEN we asked whether they would want to have an Admiral Nurse available.

So clear, simple instructions are essential. We (would have) used facilitators to lead each DEEP group's session, to guide members through the process. The small number of groups that got this done before lockdown found this worked well.

5 Analysing the data

Can be a bit longwinded.

We used Survey Monkey for our Admiral Nurse survey, to keep it quick and easy for them. But we used the free version, which limits you to ten questions, and does not provide analysis. It does provide lists of comments, but these have to be transcribed.

However, in a size limited sample (ours was 75ish nurses) it was not hugely onerous, just laborious, to put those comments, which were brief, into a Word document. Once inputted it was then easy to copy and paste wherever needed.

The benefit of the manual process is that the person doing it reads everything and gets to know the data and themes and details really well, prior to compiling the report.

I did all the analysis and collation over a couple of days (with breaks!).

6 Writing the report

Find someone who enjoys doing it and has the skills. Don't produce a report from your valuable data which no one wants to, or can, read.

Better to stick to presenting the facts/data with minimal interpretation, if you are in doubt how to write it up. Better still, find and pay someone who can do it for/with you.

I'm blowing my own trumpet, but I just happen to have the skills and work experience to do all this stuff. it's sort of bread and butter to me, and I enjoyed reactivating my brain (though I did have to hit myself a few times to get on with doing it).

7 Finally...

Make absolutely certain that all that hard (and enjoyable) work leads to worthwhile outcomes, if at all possible. Take your findings to those in positions to influence change. Use social media. Get it out there.

It's easy now to make a short film. Try recording the group/s sharing what they did, found out and enjoyed. Tweet it out. Get it on YouTube. (With consent of course).

Oh, and don't be afraid to reward those who put in the hours to make it all happen. Ok, not over the top, but it is work, and should be compensated.