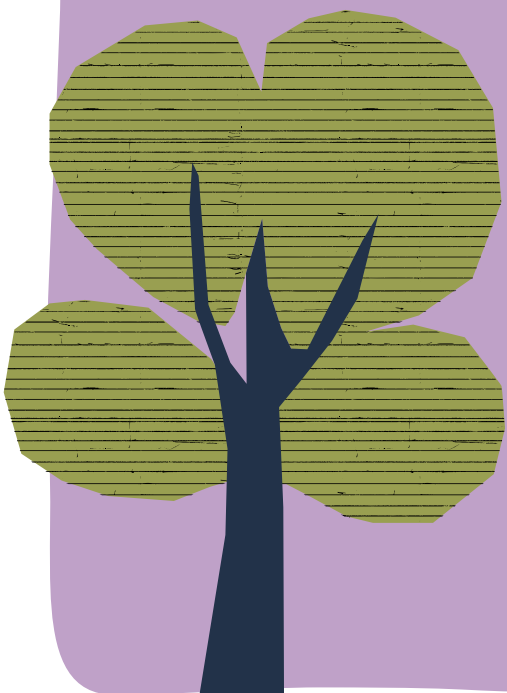


Public Involvement with people living with Dementia - Found Poetry -



We are a group of people living with Dementia, carers and researchers, working together to explore and enhance public involvement in research with people living with Dementia.

Our poems were inspired by a survey that was run as part of this project. We used a method called 'found poetry' to express our thoughts and key learnings about this topic.

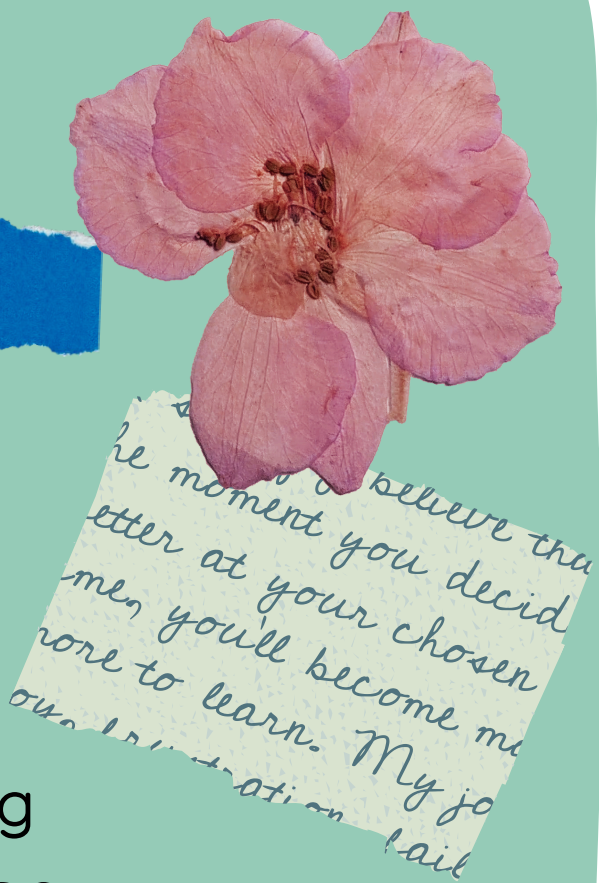


What is found poetry?

Found poetry is created by taking words and phrases from an existing text and reframing them. In our case this was a survey about public involvement with people living with Dementia.

The process involves identifying impactful words and phrases in a text, and then arranging them into a poem, with some adjustments and additions. Like a collage with words.

We do not claim to be experts in poetry, Dementia or public involvement- only our experience with it. And this is what we would like to share through this collection.



Together



Keith Oliver, Alicia Bewick, Jenny Richards, Amanda Threlfall, Julia Burton, Barbara Woodward-Carlton, Shafiq Ahmed, Elizabeth Abbott, Tanya Hynd and Naomi Morley

What being involved in research means to me

by Keith Oliver

A chance to steer
Rather than be driven,
An opportunity to learn
As well as to teach,

An invitation to feel valued
Rather than feel worthless,
An incentive to help others
Following in our footsteps,

A sense of fulfilment and hope
Positivity replacing despair,
A feeling of comradeship
Against doubts and isolation,,

An alliance of strength
Opposed to fragile dependency

A pound wisely spent
with an eye to PPI
Is likely to save two tomorrow,
An opening to reflect
and consider detail
Beyond eye catching headlines,

An enablement to think
and discuss
Rather than dwell in apathy,
A right to make a statement
Instead of remaining passive,

A quest to find answers
To overcome looming "brickwalls",
A desire to make present and future
Better than the past.



Dementia



Those who live alone
inside and out

The person I was
The person I am
The person I will be

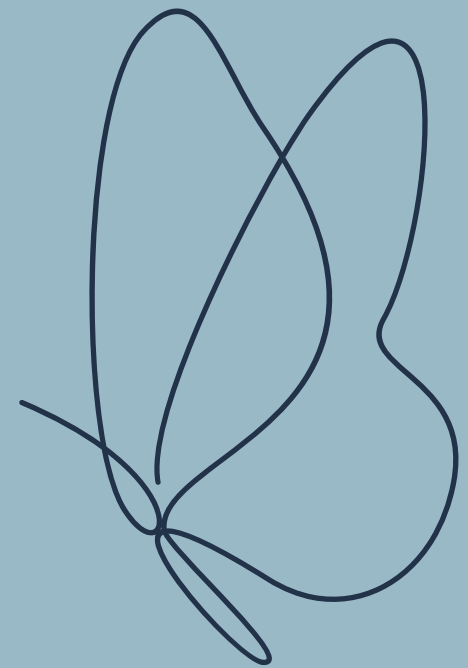
How do I tell
What do I tell
To whom do I tell

I am losing my brain!

by Barbara Woodward-Carlton

Journey

by Tanya Hynd



Not sure and don't know where to start
Wondering what is possible.

Stuck by limitations, systems barriers,
practical issues

Carers dominate the conversation,
overshadow the voices

People living alone are left out.

Overprotective gatekeepers
making presumptions.

It might be hard to navigate,
inexperience is presumed a barrier.

Just go speak to people.

Experiences of dementia is unique and personal.

Be open to learning,

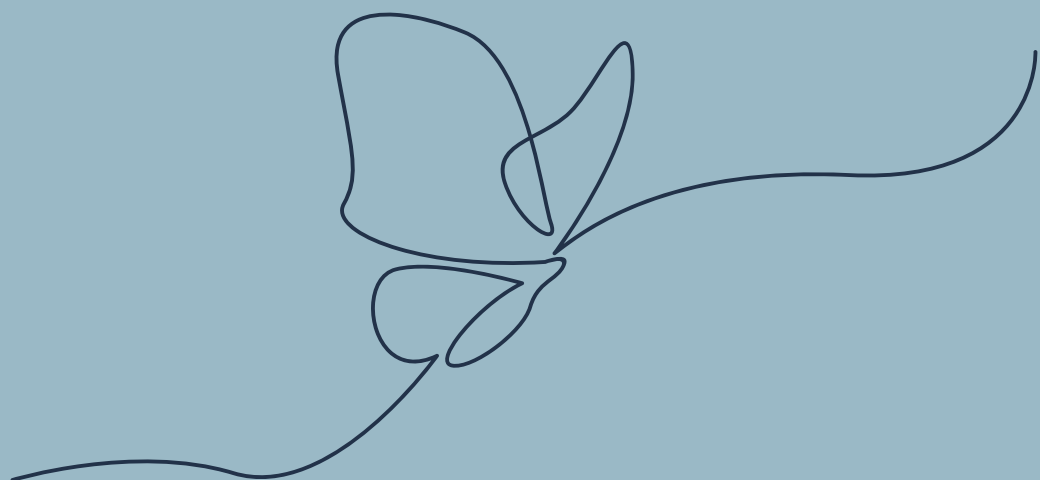
Recognise and value the potential

Don't sideline people with communication difficulties.

Find out what works, understand the needs,
learn from them.

Be humble,

it is a shared journey



Communication

by Amanda Threlfall

Lying at the heart of communication
Lies

A delicate balance between
Time, emotions, and words, and their
Impact!

Engage meaningfully,
Have empathy
Challenge barriers
Respect my dignity
Converse in my language
Listen.



My time

Time to build relationships,

finding ways to include

Time to find you,

alone they are excluded

Time to build trust,

to overcome challenges

Time to organise practicalities,

to help those that feel vulnerable

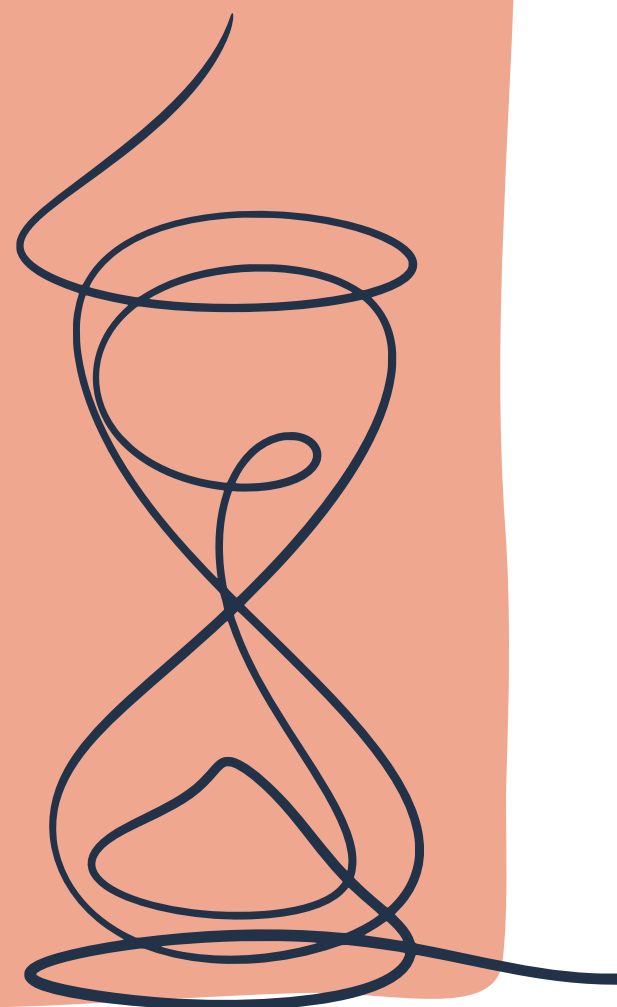
Time to allow reflection

Time to balance against bias

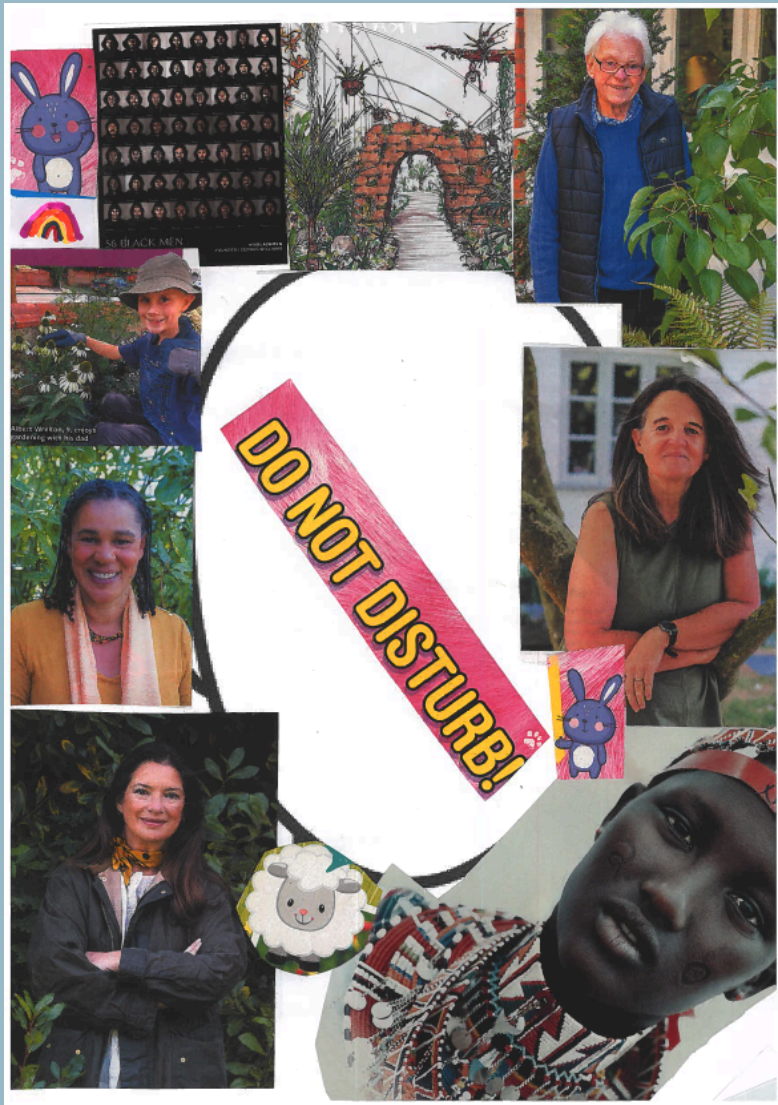
Time for heartbreak,

time for dignity

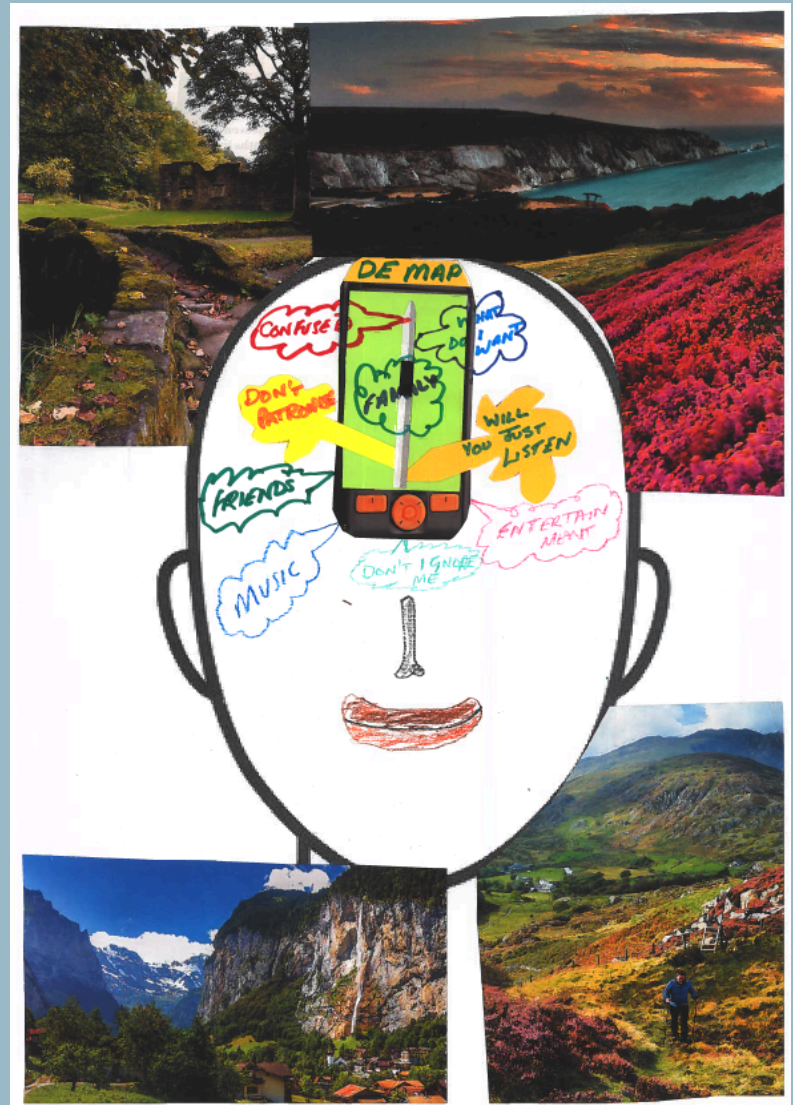
by Jenny Richards, Keith Oliver,
Alicia Bewick and Elizabeth Abbott



Our dreams for change



by Jenny Richards



by Shafiq Ahmed



by Amanda Threlfall

Invisible thief

by Amanda Threlfall

I know you're there
I can sense you
Your sinewy fingers
Ready to rummage
To steal
Another piece of me

You take advantage of
Anything not yet secure
Stripping away
The new
Leaving the old and the past
Trapping me in those days

I never know
How much you'll take the next time
How many more precious memories
You'll pilfer
I silently beg you
Just leave some of me

Not much but enough
So I remember my friends and
My family
And me
The person I used to be
And still yearn to be

Invisible thief
Get out of my life
They're coming for you
They will find a way
To neutralise you
Exterminate you

Invisible thief
F*ck you!

How things come to be

by Barbara Woodward-Carlton

Living with Dementia

A living experience

A living experience which stands out

A condition

A limitation

With a lived experience

Living alone

Alone with Dementia

A lived experience

A living alone experience

A living alone with Dementia

A voice

A voice of the person with Dementia

How things come to change



Challenge

Experience of dementia is unique and personal

Things change

Yesterday I felt unafraid

Invincible, that I could take on any

CHALLENGE

Today I feel afraid

Nothings stays the same

Experience of dementia is different in different ways,

different on different days

by Barbara Woodward-Carlton,
Amanda Threlfall,
and Julia Burton



The Cyclist

by Amanda Threlfall

Don't think of me as simple
My life is complex

Like a Tour de France cyclist
Battling the mountain stages

Bends in the road
Slow and winding

Then a rapid descent
Unpredictable, sudden drops

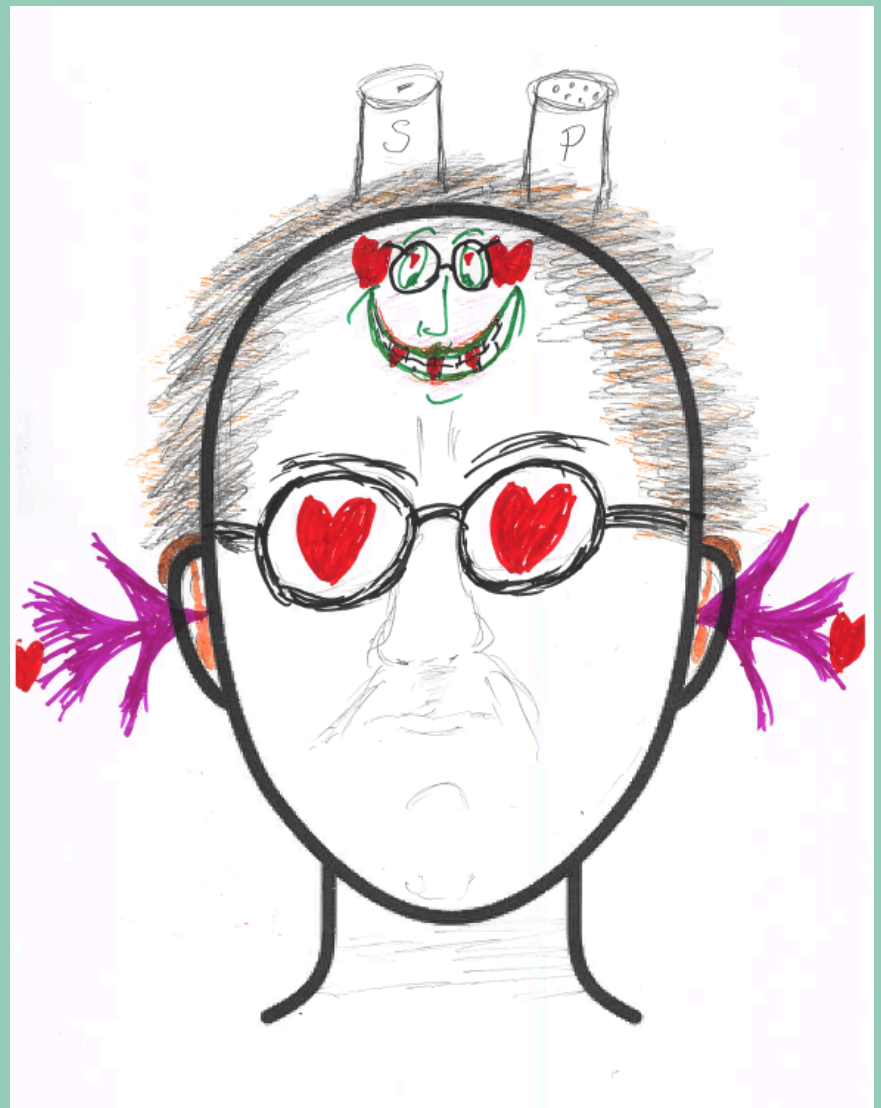
Crowds and noise give way to
Calm moments of clarity

Barriers, detours
Navigating unfamiliar, familiar terrain

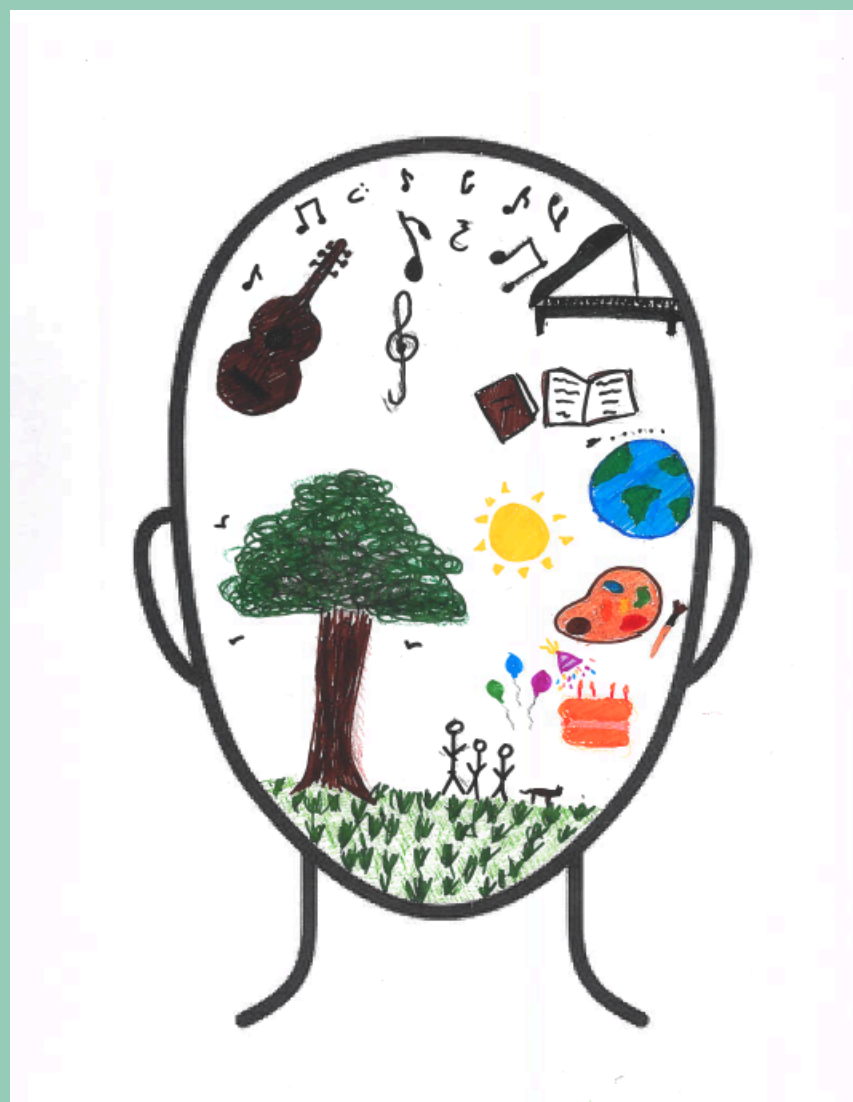
Our dreams for change



by Julia Burton



by Keith Oliver



by Alicia Bewick

Engagement in Research

by Julia Burton

Engagement in Research - a shared situation
between humans sharing motivation.

Why?

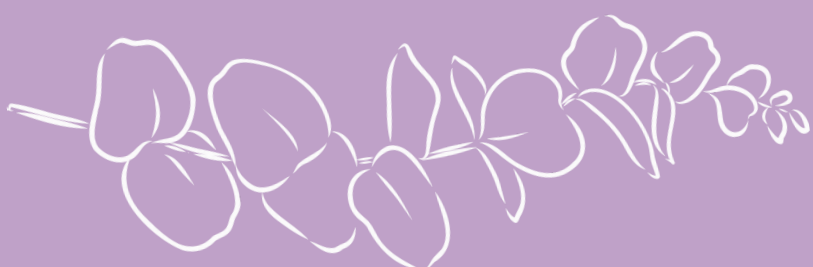
Lived experience brings emotion
Doesn't need to cause commotion:
Engagement in shared situation,
Participation in co-creation,
Providing breadth and motivation.
It's worth it!

Engagement in Research - a shared situation
between humans sharing motivation.

How?

Find the time:
Time for us, all of us;
Time to support us, all of us;
Time to build up trust between us, all of us;
Time to keep us in the picture, all of us;
Time with us is valuable for all of us.

Engagement in Research - a shared situation
between humans sharing motivation.



Acrostic

by Keith Oliver

R ecognising

E ngaging

S cience

E mpowering

A nalyzing

R especting

C reative

H ereafter

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The authors would like to thank all those who have contributed to the survey on public involvement with people living with Dementia in the Spring of 2024; and so generously given their time to support this project, participating in many conversations and inspiring this work.

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