



## **Evaluation of the Dementia Voices programme**

### **An Information pack for an external evaluator**

#### **Prepared by the Evaluation Advisory Group:**

Allison Batchelor

Chris Higgins

Julie Hayden

Lorraine Dunn

Masood Qureshi

Paul Ratcliffe

#### **Supported by**

Damian Murphy

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## **A little background information**

Dementia Voices is an initiative of [Innovations in Dementia](#) funded for 4 years by The National Lottery Community Fund running until December 2023.

Innovations in Dementia is a community interest company working across the UK with and alongside people living with dementia.

Dementia Voices developed from a desire to harness separate strands of the work of Innovations in Dementia under the one banner of [Dementia Voices](#) to create a broader platform for the voices of people with dementia to be heard and more importantly heeded across the UK. There are now 5 programmes of work under this 'banner'

- [Dementia Diaries](#),
- the [DEEP](#) network
- the [Dementia Enquirers](#) research project
- [Dementia Creatives](#) and
- [Dementia Tip Share](#)

We believe that the Dementia Voices programme can form a turning point in the history of involvement and inclusion of people with dementia in gaining increased power and control in their own lives and in shaping dementia services.



## What and who we are looking for

We are seeking someone to carry out the evaluation of the Dementia Voices programme. **We have an available budget of £30,000.** (This should include all expenses and any VAT if applicable)

**Having looked at the information within this pack, we would like you to**

- Submit a proposal to us detailing your full methodology and costs to evaluate Dementia Voices no later than **midday Friday 8<sup>th</sup> October**
- Include in your proposal a video of no more than 5 minutes introducing yourselves and outlining the proposal.
- Attend an interview via zoom with us to be held **week commencing 18<sup>th</sup> October 2021** to discuss your proposal
- Your plans will include monthly catch up meetings with the Evaluation Advisory Group (EAG) to share and discuss your progress and quarterly reports to the EAG for the duration of the work, culminating in the publication of a final report December 2023.
- Please send your proposals and videos and any questions to Damian Murphy ([Damian@myid.org.uk](mailto:Damian@myid.org.uk))



**Do YOU fit the bill? You will:**

- share our values of inclusion and involvement.
- possibly have experience in advocacy in the disability field, and/or experience in evaluation
- need the skills and resources to be able to elicit information from all of us, however impaired and a willingness to tap into the resource of peers with dementia to help with this if necessary. The nature of an external evaluator demands a questioning, inquiring mind.
- need to be organised and to make scheduled monthly sharing meetings with us as well as preparing clear updates and quarterly reports on your progress.
- recognise the very expertise of people with dementia as a resource itself - in other words we call for a little humility and the ability to listen and hear.
- have an ability to think outside the box.
- be equality oriented.
- appreciate that Dementia Voices is very much about daily lived experiences being understood, captured and responded to, so that



people's voices can help build and shape services far and wide in a more consistent manner. **We don't just want spreadsheets!**

- be willing and able to collaborate. We want you to feel comfortable and indeed encouraged to check in with us as an advisory group about any aspect of your methods at any time and we would always ensure a response from a group of us, if not all of us.

### **Our perspective.**

During the Covid pandemic, people did not stop getting dementia. Services ground to a halt in many areas leaving huge backlogs. There is clearly a need for new ways of working drawing upon our own expertise as a resource.

**There has never been a more appropriate time to escalate our voices.**

### **How we see what Dementia Voices is all about.**

We recognise that Dementia Voices is much more than putting some important projects together in an umbrella website. Below is not an exhaustive list and an ongoing dialogue across the DEEP network will no doubt add to this, but for us...

### **Dementia Voices is about a real turning point in history where we (people with dementia):**

- take the lead in everything – policy, research and decision making
- work together on an equal footing with everyone
- truly make the difference
- change the attitude of other people and stakeholders and how they treat us
- show how we can live as well as possible



- show our peers the value of being involved
- ask questions and hold others to account
- take charge
- move on from 'cafes', games and being brought a coffee and cake
- break the stigma around dementia
- matter most and become the primary focus
- are not spoken to via our carers
- are supported to make real, lasting, meaningful connections

### **The aims and expected outcomes of Dementia Voices**

#### **Aims –2 big things that we want to happen**

1. Ensure the voices of everyone with dementia regardless of situation or level of impairment are heard and listened to where they can have maximum impact.
2. Ensure that people with dementia can exercise ownership and control in the ways that best suit them.

**Objectives –in blue smaller things that we want to happen to make the big things (Aims) happen**

**Outcomes – in green what will be different if we do the smaller things (Objectives) right.**

1. **To develop new ways for capturing and channelling the voices of people with dementia at grassroots level and applying these at the national and international level**



People with dementia will have access to a wider range of **tools, resources and opportunities** for making their voices heard and to have different conversations about dementia.

**2. To increase the number of people with dementia whose voices are heard.**

More people with dementia will have their voices heard

**3. To increase the diversity of people with dementia whose voices are heard.**

A more diverse range of people with dementia will have their voices heard.

**4. To increase the engagement of stakeholders (health and social care institutions and agencies, educators, practitioners, commissioners, the media, researchers and policy writers) with people with dementia.**

More external stakeholders (hospitals, social services, local authorities, etc) will hear the voices of people with dementia, and be able to effect changes that more closely reflect the real lived experience of those who know it from the inside.

**5. To find new ways to place control of Dementia Voices in the hands of people with dementia.**

Power and control is placed firmly in the hands of people with dementia so that Dementia Voices reflects the aspirations and intentions of people with dementia.

**A Final Reminder.**



As mentioned in the cover letter we don't really need mapping and monitoring progress against these objectives. As Paul said, **'we don't want spreadsheets!'**

What we DO want is a much deeper analysis of how the voices, experiences and stories of people with dementia have been amplified; about the extent to which these voices have made a difference and why; about future potential or possible pitfalls in sustaining a broader platform for the voices of people living with dementia.

We look forward to hearing from you!

**The Dementia Voices Evaluation Advisory Group**  
**September 2021**