



# Hear our voice!

## Guidelines for involving people with dementia in policy, advisory, consultation and conference activities

Co-produced by The Centre for Economic and Social Research on Dementia, The Irish Dementia Working Group and The Alzheimer Society of Ireland.

April 2020

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As great believers in not reinventing the wheel, the IDWG have made extensive use of resources developed by DEEP. Our thanks to DEEP, The Dementia Engagement and Empowerment Project, a UK network of dementia voices. DEEP is hosted by Innovations in Dementia and has approximately 120 groups. [www.innovationsindementia.org.uk](http://www.innovationsindementia.org.uk)

### Cover image

The cover image was designed by IDWG member Marguerite Keating. Marguerite used the forget-me-not flower and worker bees. The bees symbolise the members of the Irish Dementia Working Group.

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## Introduction

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The Irish Dementia Working Group (IDWG) came together towards the end of 2012 with five members and has grown steadily since then. There are now four regional groups – East, South, West and South East, with a total of 40 active members.

The IDWG is an advocacy group of people with a diagnosis of dementia who work to share their experiences and highlight issues important to them. By amplifying the voice of people living with dementia they aim to improve understanding of the condition and supports for those affected by dementia. The IDWG works to influence public policy, raise awareness, engage in political advocacy and destigmatise dementia by speaking publicly and in the media.

As the group, and the demands on them have grown, a separate Dementia Research Advisory Group also supported by The Alzheimer Society of Ireland has been formed, which has developed a set of guidelines for involvement in research which can be found here [https://alzheimer.ie/wp-content/uploads/2020/04/DRAT\\_Guidelines.pdf](https://alzheimer.ie/wp-content/uploads/2020/04/DRAT_Guidelines.pdf)

The Irish Dementia Working Group, the Alzheimer Society of Ireland and the Centre for Economic and Social Research on Dementia are working together to develop ‘Best Practice Guidelines’ on involving people with dementia on committees, advisory groups, consultation processes and other forms of engagement. Being actively involved in these activities is very important for group members, and all speak of the benefits to them of being involved in maintaining their abilities and general wellbeing. As one member said:

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## Introduction

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**“Working with the Irish Dementia Working Group has taken me to a place I never dreamed possible but it has also given me a sense of purpose – if I didn’t have this group what would have happened?”**

The IDWG wants to ensure that this involvement continues and grows and that it is a positive experience for all.



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## Purpose and scope of guidelines

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The purpose of the guidelines is to provide practical guidance in a user friendly format for individuals and organisations who wish to involve people with dementia in their work or gain their views in a formal way.

The scope of the guidance includes the involvement of people with dementia in activities such as membership of policy groups, advisory groups and similar committees; the involvement of people with dementia in consultation processes, either individually or as members of a group; and the involvement of people with dementia in meetings and conferences as presenters, panel members or other roles. The guidance does not cover involvement in research as this has already been addressed.

The guidance is about the involvement of people with dementia, i.e. not guidance about the involvement of carers in these activities. (However, the role of carers as supporters for people with dementia in the above activities will be covered in the guidance.)

Note on terminology – the term support person is used throughout to describe the person who provides everyday support to the people with dementia. This may be the person's partner, another family member, a friend etc.

**"I know this is a progressive illness without a cure, but I also know that I need hope to live. Being an advocate and working to influence policy gives me great hope."**

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## General principles

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The guidelines are underpinned by a set of general principles which should be evident in all interaction with people with dementia.

- **Give the person a voice**

The overarching aim of the IDWG is to give the person with dementia a voice through the collective of the group and this should permeate all the interactions with the groups and members of the group. It is not about any one person and it is important to hear each person.

- **See the person**

Respect each person as a unique individual and support her/his personhood in all your interactions.

- **Emphasise the strengths and abilities of each person**

Think about what the person CAN do - not what they CAN'T. There is always a way to overcome obstacles to involvement. Provide specific support for areas that may not work so well for the person.

- **Participation is a human right**

The opportunity to participate and have one's voice heard is paramount. Value each person's contribution on its own merits. The ASI charter on human rights can be found here **A Charter of Rights for People with Dementia**.

- **Be flexible**

Remember that a person's ability to participate may fluctuate. We can all have good days and bad days. Involvement needs to be flexible to take account of this.

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# General principles

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- **Respond to each person as an individual**

The guidelines give general guidance on best practice in involving people with dementia. However, what works well for one person may not work for another so you need to check with each person what works best for them. Remember to take different cultural beliefs and practices into account as well.

- **Never judge a book by its cover!**

Don't make assumptions about what dementia 'looks like' or how well a person may appear at a meeting. It can take a lot of time and effort to prepare the work and to look good!

- **Safeguarding**

Safeguarding works with the person and those supporting them to protect them and keep individuals safe. The meeting organisers should be aware of safeguarding principles (for example, [www.alzheimers.org.uk/get-support/legal-financial/safeguarding](http://www.alzheimers.org.uk/get-support/legal-financial/safeguarding)). Ensure that measures are proportional – using the least intrusive response appropriate to the risk presented and that measures are empowering – where people are supported and encouraged to make their own decisions and provide informed consent.

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# Guidelines

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## 1. Interaction

The overall experience of involvement should be enjoyable and a positive experience for the person. One way to ensure this is with interaction that is calm, positive, encouraging and supportive. Building in time for social interaction (over refreshments) is also very important. This can allow time for people to get settled at the beginning of a meeting and for informal 'debriefing' and peer support throughout. Remember that participants may have additional needs or cultures and beliefs that need to be taken into account. Be familiar with the General Principles and implement them.



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### 2. Communication

- Ask each person how best to communicate with them and then use this information to frame any future interaction. This may be a phone call, a text, an email or a letter. It may be that the person prefers all communication to go to their support person or that they are both included in the communication. Generally after the initial contact a reminder contact (text, email or phone call) just before the event works best.
- All relevant details for an event should be provided in written format: date, time, venue, directions to the venue. Don't forget to provide the name, contact details and photo of the person organising the event. If someone else is meeting the person at a transport hub or at the venue make sure you provide their contact details and photo too. This can be very important if, for example, a taxi doesn't arrive who does the person contact? These details should be copied to the person's supporter if necessary.
- Provide adequate notice of meetings so that the person and their supporter can plan well in advance. Send the agenda and papers for the meeting well in advance – a good guide is two weeks before the meeting - so that the person has enough time to prepare and to get some assistance in their preparation if necessary. Send a reminder with the details of the meeting a few days in advance.
- Communicate clearly what is expected of the person – is it sharing their views in a group, is it speaking at a meeting or conference? Many people with dementia do not have much experience of this type of activity so don't assume they will know what is required



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or expected. Make sure adequate time is scheduled to allow the person to present if that is what they have been asked to do. Most people with dementia prefer to make an oral presentation rather than use PowerPoint, which may take extra time. Please do not make a last minute change to the time that has been allocated to the person. They have prepared in advance and it is stressful to make changes. Be open to using other forms of contribution instead of a presentation which can be daunting for many. A 'mini-interview' and/or contribution as a panel member can be useful ways of hearing directly from people with dementia without them having to stand up and present. Remember to share the questions in advance if this format is being used.

- Check with the person in advance if they want a prompt to keep them 'on track' if they are making contributions at a meeting. This may be support that they seek from a peer or another person attending at the meeting.
- Remember to provide feedback on the event directly to the person who has participated. They are interested to know what happened as a result of the meeting or event.
- With verbal communication, speak clearly and be conscious of accents. Use short sentences. Avoid the use of jargon and acronyms. Use plain language. Be aware the person may have hearing difficulties.
- All written and verbal communication with the person should follow the relevant principles described in Section 1. Be aware that the person may have visual impairments or their dementia may affect

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their ability to read and arrange appropriate alternatives to written documents or support (such as someone to read the documents for the person). Ensure the obtaining and retention of contact details adheres to GDPR guidance.

- Detailed guidance on the use of language is available at: [www.dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf](http://www.dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf)

### 3. Providing information - short and to the point

- Involvement often means that written information is provided to the person with dementia as instructions, as background information, for providing consent or as a document to comment on. Be conscious of the volume of written material you are providing in advance and don't over-burden participants. Be aware that content can sometimes be off-putting and potential participants might feel they have nothing to offer on a topic. Emphasise that information is to help the person prepare and does not have to be read in advance – what is important is their view and there is no right or wrong answer. Avoid using the contribution of participants in an opportunistic or sensationalist way.
- Detailed guidance on producing dementia-friendly information, has already been prepared by DEEP and can be found here: [www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf](http://www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf)



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### 4. Venue

- There are many things to consider in the logistics of a meeting venue including; accessibility, signage, lighting, quiet space, food and beverages and more. Relaxed and friendly venue staff can make a big difference. Have a greeter at the entrance to direct participants to the room. If regular meetings are being planned, have them in the same venue as far as possible. Make sure the room size is adequate for the group, has natural light and is near to the lifts. Make sure water and juice is available as well as tea and coffee. All reasonable dietary requirements should be accommodated. Make sure it is easy to find the venue and easy to find the entrance to the venue. Signage to and from toilets is very important. Try to have a run-through at the venue in advance if possible and especially if large numbers of people with dementia are expected.
- Be conscious of noise levels in the venue. It can be difficult for the person with dementia to concentrate and follow conversations if there is a lot of background noise and/or if more than one person is talking at once. If booking accommodation for a person with dementia, remember to check their specific requirements and to book a room that is close to the lift and reception if possible.
- Detailed guidance on dementia-friendly venues, has already been prepared by DEEP and can be found here:  
**[www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf](http://www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf)**

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- If the meeting is taking place by video call (Zoom, Google Hangouts etc.) please take the time to check if the person with dementia has access to the internet and a device to join the call. If the person is able to join a video meeting, set up a test run before the actual meeting. Do the test at least a day before so there is time to solve any difficulties. Take the time to talk through the platform being used, whether it is necessary to download an app in advance. Also discuss video call etiquette which may be new for the person (muting microphones, how the meeting will run, who will facilitate). Ensure there is a named person on the call (aside from the facilitator) who can offer tech support to join the meeting, or support any issues with microphones and cameras during the meeting. Be aware that an online meeting should run at a gentle pace – many people with dementia rely on body language and other non-verbal methods of communication to navigate a meeting and this is more difficult on a video call.



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### 5. Travel

- If you are arranging travel for the person with dementia send a written itinerary which includes all the relevant details. A contact number is very helpful so the person can call at any stage. It can also be helpful to send the person or their support person a quick text to check on how they are getting on in their journey. The IDWG has worked with Irish Rail to develop top tips for travelling with Irish Rail which can be found on the ASI website.
- Although you may be arranging travel for a person, it can be helpful to go through the journey details for the person to help them prepare – especially if the person is using public transport. This involves the person getting from their house to the mode of transport and then from the mode of transport to the meeting venue. Practical reminders like having change for tickets or parking meters can be helpful. Remember to build sufficient travel time into the overall itinerary of the day so that the journey is as relaxed as possible for participants.
- Clear directions to the venue from rail or bus stations are essential, or recommendations on nearest car park or taxi rank. Make sure the entrance is clear if there are multiple entrances.
- Avoid excessive distances for participants if possible. The development of regional Dementia Working Groups means that there are people around the country who may be more easily able to participate in your area. Avoid travel arrangements which require a very early start. It is difficult to participate in a full day if the person has been up since 4am. Arrange for accommodation the night before if a very early start is required.

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### 6. Consent

The involvement described in these guidelines excludes involvement in research projects which has its own well-developed consent processes. Consent for participating in a meeting and/or sharing views on a topic is a different process, with the focus on ensuring the person understands what is being asked of them. However, anything which directly identifies the person, either through the use of their image, their voice or their name (for example, in a piece of film, a photograph or a written quote) should be based on written consent so that the person knows they will be identified and how widely their image/name will be shared. A useful 'consent checklist' is:

1. The consent process is continuous and should be continually reviewed.
2. Clear and accessible information should be provided to the person to ensure that they understand what is being asked of them.
3. Spend time getting to know the person to ensure that they are comfortable with you and trust you.
4. Written consent is particularly important for publicly available material.
5. If appropriate, involve family members or other supporters in the consent process.





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## Guidelines

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### 7. Support

Establish:

1. what type of support the person with dementia may want or need so that they can participate fully in the event/meeting and
2. who they want to provide that support.
  - For example, support for participation may involve support with travel, or may involve some sort of support to participate in the meeting. The support may be provided by the person's usual carer/support person or a member of the organising team or a combination of both. For example, a support person might accompany the person with dementia on their journey to the venue and support at the event may be provided by the organising team. Make sure the support person has all the relevant information in advance of the meeting and has been copied into all communication (see 2 and 3 above).
  - Determining the number of support staff depends on the numbers of people with dementia at the event and their needs. However, if there is more than 2-3 people it is recommended to have someone who is available for support in addition to the meeting facilitator/organiser/chair. This allows for someone who can meet participants at the entrance to the venue or who can show participants to the toilets etc. while someone is also in the meeting room.

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- Be aware that participants may need some time out in a quiet space and identify how this can be facilitated at the meeting venue. A member of the organising team should be available in the event of a participant becoming upset at a meeting. While an informal chat may be sufficient to support the person, contact details for further support should be provided to the participant if necessary.
- De-briefing is important. Identify someone who participants (and their supporters) can link with after meetings or events to talk through the experience and to recap the main points or agreed plans. This is highly valued by participants and supporters who find it very helpful.

### **8. Recognition and acknowledgement**

All participation and contributions to meetings (including policy consultations, steering groups etc.) or events should be acknowledged. Depending on the person's preferred mode of contact, a text, email, call or thank you note should be sent. Feedback and personal recognition of the person's contribution lets them know their contribution is valued.

If relevant, the contribution of participants with dementia should also be formally acknowledged in written reports and papers. Check with participants if they want to be named individually if this is appropriate to the format.

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## Guidelines

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### **9. Payment/expenses**

Where possible expenses such as travel, refreshments and accommodation should be covered in advance so that participants do not have out-of-pocket expenses. Be aware that many people with dementia live on limited incomes and even minor expenses that are required up front and refunded later, may present a barrier to participation.

If not covered in advance, all out-of-pocket expenses required for participation should be fully refunded promptly and where possible, paid within a two week period. Depending on the work involved and the funding available to the project, recognition of the participant's time in the form of a voucher or honorarium is welcome.

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## Guidelines

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### **10. Different types of involvement:**

This section provides additional detail depending on the specific type of involvement required, e.g. a consultation, meeting or conference. General guidance for all forms of involvement includes:

- Remember it can be stressful getting to a meeting – build in time at the beginning for people to get settled and establish a warm, friendly atmosphere within the meeting room
- Make sure the person knows what to expect and what is required of them. Don't surprise participants on the day with new items for discussion – provide a written agenda in advance.
- Make sure everyone in a meeting introduces themselves and their association with dementia. This includes the person with dementia. They are present because they are living with dementia and should be introduced as such. For example, “this is [name], who is living with dementia and is a member of the Irish Dementia Working Group”. Name badges are helpful.
- Be aware that participants can spend a lot of time preparing for a meeting and may be stressed or anxious about taking part.
- It's good practice to go around the table and offer everyone the opportunity to participate at least once – appropriate encouragement from the chair and peer support is important.
- Find out about the abilities, skills and interests of potential participants and use them if relevant, for example, someone who has a background in art or design could have unique insights in issues relating to design.

## Guidelines

- Recap the meeting or discussion at certain points and/or at the end so people can make a contribution they may have forgotten earlier.
- Start meetings 'on the hour' – meetings scheduled for quarter past or quarter to for example, can make it difficult to remember when it's starting. It's important to start the meeting on time.
- Ensure meetings do not last too long and regular breaks are scheduled.
- Ensure participants know how long the meeting will last. This should be in advance documentation and agreed at the beginning of the meeting.
- Send a written note or minute of the meeting with actions points so that participants will have a record of further actions if required.



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## Guidelines

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- **Advisory group or steering group** As well as the principles in section 1 and the guidance on meetings in this section, detailed guidance on supporting the participation of people with dementia in advisory groups has been prepared by DEEP and is available here: [www.dementivoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance\\_involvingpeoplewithdementiainadvisorygroups.pdf](http://www.dementivoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf)
- **Consultation** As well as the principles in section 1 and the guidance on meetings in this section, detailed guidance on supporting the participation of people with dementia in a consultation process has been prepared by DEEP and is available here: [www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf](http://www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf)
- **Providing feedback on materials** As well as the principles in section 1 and the guidance on meetings in this section, detailed guidance on writing dementia friendly information has been prepared by DEEP and is available here: [www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf](http://www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf)



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## Guidelines

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- **Conferences** If a person with dementia is presenting, be precise about what you want them to talk about and for how long and whether they will be asked to respond to questions. If people with dementia are present, ask other speakers to present in an appropriate manner and avoid jargon filled, technical PowerPoint slides. As well as the principles in section 1 and the guidance on meetings in this section, detailed guidance on supporting the participation of people with dementia in conferences has been prepared by DEEP and is available here: [www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Conferences-and-events.pdf](http://www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Conferences-and-events.pdf)
- **Filming** As well as the principles in section 1 and the guidance on meetings in this section, detailed guidance on supporting the participation of people with filming has been prepared by DEEP and is available here: [www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-For-film-makers.pdf](http://www.dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-For-film-makers.pdf)

**"After my diagnosis people kept offering me tea, and while I like tea I can do a lot more than sit down with a cup of tea. Becoming an advocate has been life-changing. It gives me a chance to do radio interviews, public speaking and be involved in consultations on policies that affect people with dementia. Now, I am almost too busy for those cups of tea!"**



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**HR<sup>B</sup>** Health  
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