Document Title	SPIN-D Language and Terminology – Guidelines for Researchers and Conference Presenters
Number and Category	1e. Category E: SPIN-D - Developed Resources
Status	V1
Date	26.06.2024
Next Actions	Review Q2 2026
Developer (2a)	RE: TIDE; DG: SPIN-D
Contributor / Reviewer (2a)	CG: SPIN-D

SPIN-D NETWORK+ | Sustainable Prevention, Innovation and Involvement for Dementia

LANGUAGE AND TERMINOLOGY – GUIDELINES FOR RESEACHERS AND CONFERENCE PRESENTERS

Language and terminology

Authentic equality, inclusion and involvement is at the core of the SPIN Dementia Network and requires a willingness from speakers and presenters to adapt their presentations and content to ensure everyone feels like an equal partner.

Please prepare presentations and activities that are suitable for a diverse public audience. Expect that the audience will include people who have cognitive difficulties and sensory impairments, and also people for whom English is not a first language. Think about the terms you use, keep your message jargon free, simple and clear.

Avoid the use of acronyms; if any acronyms or abbreviations are used, please ensure that you have time to explain them. Pictures and graphics are welcomed, but please leave time to describe what they show.

Unless your presentation is on the topic of epidemiology of dementia, please **do not** include general background statistics on dementia. Please only include specific background that is directly relevant to your topic.

Remember that the theme of the conference is ‘fiction, fact *and hope*’. We wish to take an anti-stigma position towards cognitive impairments. Please avoid terms such as ‘the burden of dementia’. People at risk of dementia and those living with the diagnosis often fear becoming ‘a burden’ and we do not wish to reinforce a ‘dementia as burden’ stereotype. We are not shying away from the challenges of living with a dementia diagnosis, or caring for a person with dementia. However, we want to demonstrate that it is possible to speak about dementia in a way that recognises the *person,* irrespective of their cognitive status. We are looking to showcase developments, breakthroughs and realistic hope for living well as you can.

Together in Dementia Everyday (TIDE) has created a specific guide around the use of language and terminology

LANGUAGE AND TERMINOLOGY – GUIDELINES FOR RESEACHERS AND CONFERENCE PRESENTERS

INTRODUCTION

Language matters. The words we use can help – or hurt. This is particularly the case when referring to people from marginalised groups or who experience stigma because of their condition or state of health. Some groups – such as health professionals and academics – use their own language, full of specialist terminology or acronyms which can alienate those who do not speak it.

How we deliver the words matters too; we must not assume that language is accessible to all. People with visual or hearing impairments face unique challenges when engaging with spoken, written, or environmental communication. For these individuals, accessibility is not an add-on — it is fundamental to true inclusion.

This guide is an attempt to provide practical help and advice for researchers and presenters on the best way to talk or write about their work that is inclusive and easy to understand. It is based on what people with dementia and their carers have told us.

TALKING ABOUT DEMENTIA

Over half of us know someone – a family member, friend or neighbour – who is living with dementia, yet despite this there is still a lot of fear, ignorance and stigma attached to the condition. Even the word 'dementia' itself can be frightening; generally, the terms 'demented' or 'dement' should not be used, although some people with dementia may choose to do so as part of their identity.

Some dos and don'ts:

- Remember that someone with dementia is first and foremost a person; do not use dehumanising language or talk about them as if they are not there
- Dementia is an umbrella term for over 200 different types and sub-types. Do not use 'dementia' and 'Alzheimers disease' indiscriminately; be clear about whether you are talking about dementia as a syndrome or a specific condition
- Similarly, do not refer only to memory problems when talking about dementia; for many people with dementia, especially younger people with rarer forms of the condition, memory is not the primary problem.
- Don't refer to people with dementia as 'sufferers'; whist some individuals do suffer from their condition, this description should not be applied generically.
  Many people with dementia live active, fulfilling lives without any suffering.
- Better descriptors are 'people living with dementia' or 'people living with a dementia'
- Similarly, 'dementia patient' and 'service user' should not be used as a universal descriptor of all people with dementia. Again, 'people with dementia' is a preferable term. If you are talking about a particular individual or group, find out how they would identify themselves
- The term 'carer' is often used to refer to both paid staff and unpaid family carers or friends. Make sure you are explicit in your descriptions: use 'paid staff' or 'paid support staff'; and refer to 'unpaid carers' or 'families and friends', depending on the context
- The term 'carer' is not meaningful within some cultures and languages where the use of kinship terms is preferred (wife, husband, daughter-in-law etc).
- Also, use of the term 'carer' can increase a sense of disability in people with mild cognitive impairments or early dementia – in this case the term 'supporters' is suggested.

TALKING ABOUT DEMENTIA RISK

When talking about dementia prevention, or dementia risk reduction, please bear in mind that people with the diagnosis may be present as well as people who are experiencing a high level of dementia-related worry.

We are seeking to take an anti-stigma position towards dementia. We encourage you to speak about dementia as something that may affect any of us. *We* might develop dementia rather than 'they' being people who might get 'it'. Please use neutral language and avoid emotive terms burden, 'rising tides' or 'tsunamis'.

Please also bear in mind that our knowledge of dementia prevention is still in its infancy. There are risk factors *associated* with dementia at a population level, but, aside from the rare genetic conditions, we are still not able to predict dementia at an individual level.

Do not suggest that any one particular lifestyle will 'save' someone from dementia of or imply that any particular lifestyle might 'cause' dementia; it is easy to imply that dementia is self-inflicted and could be avoided.

THE LANGUAGE OF ACADEMIA

It is easy to slip into familiar terminology, acronyms and descriptors, especially when talking to fellow academicians and clinicians.

Some practical tips:

- Avoid dehumanising technical terms like 'dyads' when referring to a person with dementia and their family carer; they are people first and foremost, as well as being research participants
- If you must use acronyms, explain the first time you use them and remind your audience later. Examples include: ECR (Early Career Researcher); PI (principal investigator); PPIE (Public and Patient Involvement and Engagement); RCT (Randomised Control Trial)
- Don't assume everyone has perfect hearing and eyesight! Hearing and vision impairments are incredibly common as we get older, and they frequently cooccur in people living with dementia (World Health Organization, 2021). These sensory changes do not just affect communication — they can deepen feelings of confusion, isolation, and disconnection if not acknowledged and supported.
- Describe visual content out loud e.g. say: *"This slide shows a bar graph comparing diagnosis rates over five years"* rather than assuming everyone can see or interpret the image. This ensures inclusion for those with visual impairments or cognitive processing challenges.
- Be clear whether you mean 'engagement', 'participation', 'involvement' or 'co-production' – they should not be used indiscriminately as they mean different things.