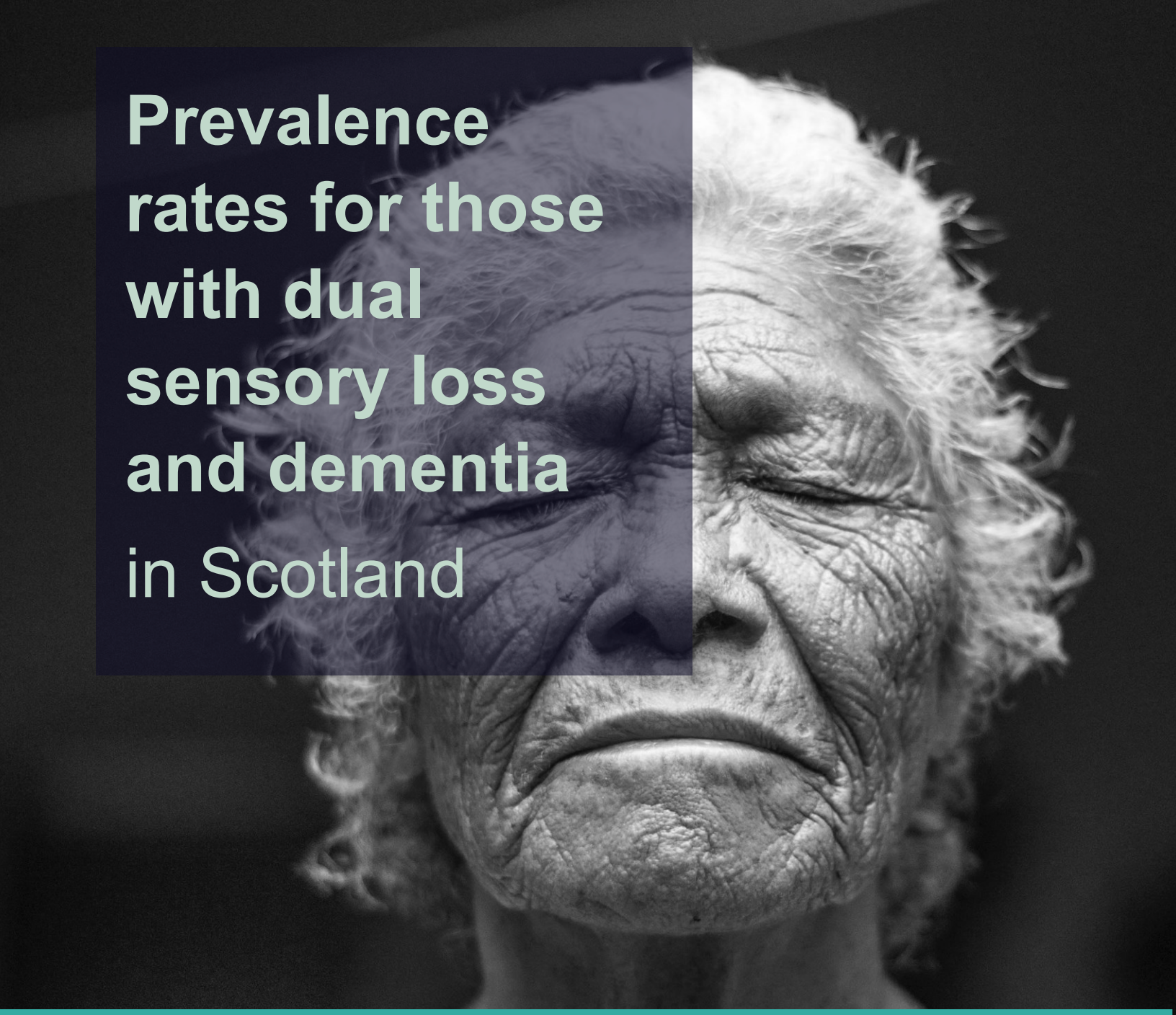

Prevalence rates for those with dual sensory loss and dementia in Scotland

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Foreword

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This research report on the prevalence rates of those with dementia and dual sensory loss comes at a time when Scotland is managing its way forward post pandemic, facing economic constraints with the rising cost of living crisis and uncertainty in world politics with further international conflict. There is a strongly felt collective will to commit to a recovery which makes the changes necessary for all people in Scotland to thrive.

In Scotland the ageing population challenges us to keep people active, working longer and enjoying life. Along with the many positives of living longer, age can be often associated with living with and managing long term conditions.

Dementia is a long term and progressive condition and over time abilities and skills may deteriorate. There is a significant element of sensory loss that is age related and the report highlights the estimated numbers with dual sensory loss. A conservative estimate of 1.4 million Scots with hearing and/or sight loss is a significant proportion of the population to ensure services and support work well for.

We believe society needs to move further towards the social model of disability to enhance and assist this change positively. By identifying the barriers which prevent people from participating fully in society and removing these barriers. The mainstreaming of these issues would also address a range of communication and language barriers our future, diverse Scotland faces.

This report provides prevalence estimates for the number of people living with sensory loss and dementia in Scotland. Separate figures have been calculated for each Local Authority and are broken down into age and gender. Using future population estimates from the National Records Office of Scotland (NRS), it has been possible to project these figures, giving an indication of where future service provision would be needed. The findings can contribute to both national and local planning and ensure the lived experience of people experiencing sensory loss and who are living with dementia is at the heart of any change.

1. Introduction

This research on dual sensory loss (also known as deafblindness) and dementia has been commissioned to address the lack of prevalence data in Scotland. Chapter two of this report provides background on the definition and categories of dual sensory loss/deafblindness. For the purposes of this research, which is essentially dealing with gathering data on an ageing population, the term 'dual sensory loss' was considered to be more applicable and is the term that will be used throughout this report. There is currently no record of how many people in Scotland are living with dementia and dual

> "To plan health and social care management for an increasingly older population, it is essential to have a detailed understanding of the regional prevalence of dual sensory loss and dementia."

sensory loss. How can the needs of this group of people and their unpaid carers be met if numbers are not known? This collaborative research aims to provide robust prevalence estimates for the number of people living with dual sensory loss and dementia for each Local Authority in Scotland.

There is a known association between hearing loss and dementia, and it is thought that untreated hearing loss may be a risk factor for cognitive decline (Dawes, et al., 2019; Shen, et al., 2018). Hearing loss has been considered to be a potentially modifiable risk factor for dementia (Livingston, et al., 2017; Livingston, et al., 2020)

The link between hearing loss and dementia is now known, leading to an increasing body of research on the topic. Research studies exploring issues around dual sensory loss and dementia are being undertaken Worldwide. However, there is a noticeable gap in research specific to Scotland. In order to plan health and social care support and services for an increasingly older population, it is essential to have an understanding of the regional prevalence of dual sensory loss and dementia.

2. Deafblindness / dual sensory loss

The definition of deafblindness (or dual sensory loss) is problematic. While there is no global consensus, the Nordic definition, revised in June 2016, is widely accepted. Recently endorsed by the World Health Organisation's International Classification of Functioning, Disability and Health (ICF), the definition is noted below:

> Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability (The Nordic Definition of Deafblindness)
> Nordic Welfare

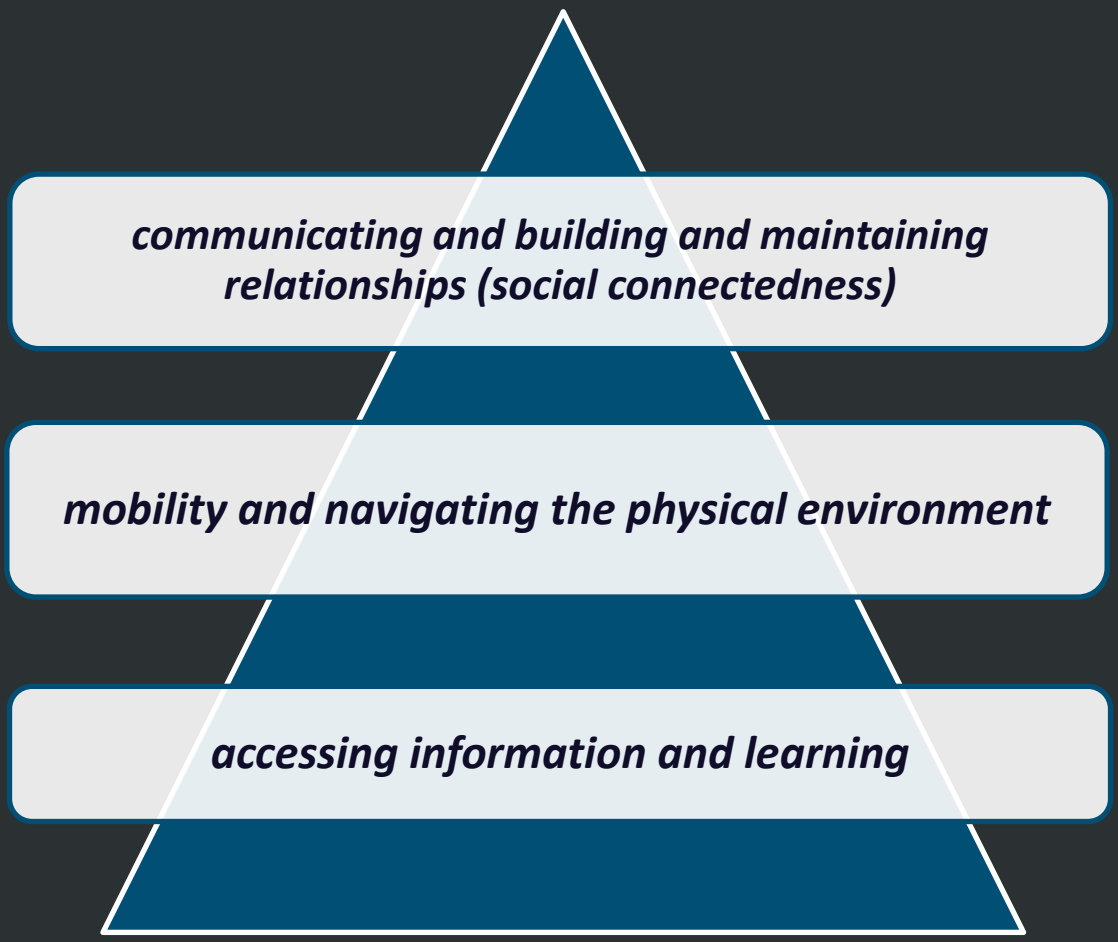
The definition goes on to state:

> To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation, and the ability to move around freely and safely. To help compensate for the combined vision and hearing impairment, especially the tactile sense becomes important. (The Nordic Definition of Deafblindness)
> Nordic Welfare

For the purposes of this project, the definition of deafblindness as set out in the Deafblind Scotland toolkit will be used, and is noted below:

> Deafblindness is the combined loss of both vision and hearing. For some people this may be a complete sensory loss whilst for others there may be some residual sight or hearing that can be used. Deafblindness has been defined in several ways but in understanding the impact on people's lives it is important that it is not thought of in terms of two single sensory losses as this uniquely disabling condition is greater than the sum of its parts. When an individual experiences a single sensory loss or are Deaf from birth they often cope by making the best use of their other senses however, with a **dual sensory loss** this coping strategy becomes less effective.

The combination of sensory losses can result in significant difficulties in areas of everyday life, including:



[**Graphic** showing a pyramid with three text boxes in front. Each text box contains one of the three significant difficulties people with dual sensory loss face in everyday life: 'communicating and building and maintaining relationships (social connectedness); 'mobility and navigating the physical environment' and 'accessing information and learning'.]

Deafblindness can happen at different stages of life and the age of onset of a person's visual impairment and hearing loss (or Deafness) can have a

profound impact on the consequences of deafblindness. This is particularly the case in relation to communication and language development. It therefore can be important to distinguish between:-

Congenital deafblindness – where a child is born Deaf with a visual impairment or where a child acquires hearing loss and a visual impairment at an early stage in life before the development of language. Occurring at a pre-lingual stage this form of deafblindness requires the child to develop language whilst deafblind.

Acquired deafblindness – where vision and/or hearing loss is acquired during the course of life following language development, where language maintenance or adaption is the focus. An individual may already have one sensory loss and acquire a second during their life or both senses may deteriorate across life.

Usher Syndrome – is a genetic condition which causes hearing loss from birth, and a later progressive loss of vision due to Retinitis Pigmentosa (RP). There are three types of Usher Syndrome (see **Part 3 Tools and Resources** for Key Terminology).

CHARGE – is a genetic syndrome, each individual will have a varying degree of impairments and medical conditions, that can be linked to a recognised pattern. Most people with CHARGE will develop hearing impairment, vision impairment, and balance problems, along with life-limiting medical conditions from birth.

While, as has been stated, the Nordic definition is endorsed by the World Health Organisation, has wide support globally and most professionals in the field adhere to the Nordic model, there is as yet no consensus on a clinical definition of deafblindness in Scotland, Deafblind Scotland state:

> In the absence of this a commonly adopted definition is that deafblindness is: 'The loss of functioning in one sense [that] cannot be compensated for with the other sense, resulting in a distinct disability' (Guthrie, et al., 2016).
>
> Deafblind Scotland

3. Background and rationale

Since the work of the Lancet Commission (Livingston, et al., 2017; Livingston, et al., 2020), a strong evidence base demonstrating the potential link between age related deafness and dementia has been established. In 2021, The Life Changes Trust funded a deafscotland project to find out the prevalence of deafness and dementia in Scotland. It was clear that, in order to plan health and social care for an increasingly older population, there needed to be a detailed understanding of the regional prevalence of these conditions. Being increasingly aware of the links between deafness and dementia, it became apparent that research into the regional prevalence rates for both was necessary to inform anticipatory planning.

The deafscotland research project looked at the four pillars of deafness: namely Deaf people who are British Sign Language users; those who are hard of hearing, those who are deafened and those who are deafblind (have dual sensory loss) and gained estimated figures for those with hearing loss and dementia.

It was found that no data is kept on these conditions at GP level and so no prevalence rates are at present known. It was however possible to use robust modelling techniques to obtain figures for the largest 'hard of hearing' category of deafness. Using population statistics, it was possible to break down age-specific incidence rates for each of the 32 Local Authorities. It was further possible to provide future detailed estimates for each Local Authority (again using population statistics) to enable them to plan for future service provision.

The 'Deafness and Dementia: Predicting the Future for Scotland' report highlighted the need for robust prevalence figures across the spectrum of deafness. Due to funding constraints, it was only possible to model figures for the largest of the pillars of deafness – people who are hard of hearing. Having modelled the prevalence figures for this category, however, it was evident that it would be possible to build upon the learning and apply the same methodology to produce likely numbers for those with dual sensory loss and dementia for each of the 32 Local Authorities in Scotland. These figures would be broken down by age and, using official population statistics, future estimates could be

provided, enabling anticipatory planning, and ensuring service provision to suit the needs of each Local Authority.

There still needs to be greater awareness of how dual sensory loss affects people with dementia, so that health and social care services, as well as community support services, can be accessible for and meet the needs of people with dementia and dual sensory loss. For this reason, it is important to establish a knowledge of the number of people living with dementia and sensory loss in Scotland at present and the future projection.

The modelling used to produce these figures could be updated on a continuous basis as soon as new Scottish government data is released, thereby ensuring a legacy of robust estimates continued.

4. Literature overview

To show how the findings within this report fit into the wider research evidence base, this section will provide a general overview of recent literature themes on the topic of dual sensory loss and dementia.

Firstly, there is lack of consensus on the actual definition of dual sensory loss and this is reflected in literature. For example, an excellent summary of the debate around definition can be found in a 2019 editorial piece by Dr Saskia Damen which appeared in the British Journal of Visual Impairment. Here, it is argued that, apart from the Nordic countries, there is no consensus in definition and identification of dual sensory loss:

> "The prevalence and incidence rates of deafblindness are unknown in many countries and deafblindness can be overlooked, especially in settings for people with intellectual disabilities" see (Fellinger, et al., 2009) **and older adults** (Roets-Merken, et al., 2017) see (Roets-Merken, et al., 2014) (Ravenscroft & Damen, 2019).

A good example of argument on the need for clear guidelines on definition can be found in Damen's earlier work, co-authored with Ask Larsen in 2014, where it is stated:

> “The results of this study call attention to a scientifically inadequate approach to the study of DB [Deafblindness] and CDB [Congenital Deafblindness]. Findings indicate that clear guidelines for sample descriptions of the DB and/or CDB populations are needed” (Larsen & Damen, 2014).

The findings from this work go on to state specific recommendations:

> “It is suggested that studies including DB and CDB participants provide the following information: definitions of DB and CDB used; severity of sensory impairments; level of sensory ability in relation to mobility, access to information, and communication; age at onset of DB; and communication as well as language ability at onset of DB” (Larsen & Damen, 2014)

In a study published this year, the same arguments are echoed. Minhas et al argue that ‘there is a lack of clarity for objective criteria or accepted definition for deafblindness or dual-sensory loss’ (Minhas, et al., 2022).

There is a tranche of research that discusses the potential effectiveness of interventions in potentially delaying the onset of dementia in people with dual sensory loss. For example, a recent study into the association of dual sensory loss and limitations of function argued that adults who have dual sensory loss had more functional limitations in comparison to those either with a single sensory loss or with no sensory loss. The study recommends that:

> “Strategies to improve visual and/or hearing function (e.g., sensory aids, rehabilitation) could potentially help prevent or minimize disability, even among those with dementia.” (Assi, et al., 2021)

Furthermore, in a study of US Medicare beneficiaries, it was found dual sensory impairment was prevalent in older adults and associated with increased risk of dementia. The findings suggested that sensory interventions for older people with dual sensory loss were a viable option to consider in terms of potentially delaying the onset of dementia (Kuo, et al., 2021).

The link between dual sensory loss and dementia and cognitive decline has been gaining momentum. For example, in an extensive study which involved 19,618 respondents who were part of the Health and Retirement Survey. Respondents self-reported sensory loss and the study looked at the link between self-reported sensory loss and risk of later cognitive decline. Results of the study argue that:

> "Respondents with dual sensory impairment at baseline were 38% and 26% more likely to develop possible CIND and probable dementia, respectively, than those with no sensory impairment."

It was suggested that further research into the association between single and dual sensory loss should be carried out in order to determine if any interventions would be beneficial. Consideration was also given to at what age these interventions would be most helpful in potentially reducing the impact of cognitive impairment and dementia (Maharani, et al., 2020).

Systematic Scoping reviews provide a wealth of information and the recent study 'Cognitive Impairment in Older Adults with Concurrent Hearing and Vision Impairment: A Systematic Scoping Review Protocol' is no exception. While this review does not deal with dementia per se, there is obvious relevance with cognitive impairment. The review concludes that:

> "…individuals with DSI [dual sensory loss] experience varying degrees of functional limitations, which impede communication, information access, independent travel, and other activities of daily living These limitations contribute to reduced social participation and pose a higher risk of social isolation, depression, and cognitive impairment. Evidence suggests a strong association between sensory impairment and cognitive impairment." (Jaiswal, et al., 2021).

In a 2020 study, Hwang et al argue that, while hearing loss and loss of vision have been associated with dementia, there is more research needed to establish the association between dementia and dual sensory loss. A total of

2,051 respondents took part in this research which used the Gingko Evaluation of Memory Study (GEM) as a base line measure. It was found that:

> "Older adults with DSI [dual sensory impairment (sic.)] are at a significantly increased risk for dementia. Further studies are needed to evaluate whether treatments can modify this risk" (Hwang, et al., 2020) .

Research looking at how dual sensory loss is managed in Care Homes has been growing in recent years. For example, the need for social engagement of nursing home residents with dual sensory loss was emphasised in a 2016 study which monitored a cohort of care home residents for a year. It was found that residents with dual sensory loss had a larger amount of decline in cognition over the year. This was in comparison to residents who had hearing or vision loss and those without sensory loss. The study found that social engagement lessened cognitive decline in residents with dual sensory loss, arguing that

> "… residents with dual sensory loss might cognitively benefit from interventions to improve involvement in social life at nursing homes" (Yamada, et al., 2016).

On a similar theme, discussion focusses on the risk of social isolation for older people with dual sensory loss and the impact that has on health and cognitive decline. Within this qualitative study involving long term care residents who use a self-management programme, where findings show:

> "older adults [with dual sensory loss] feel threatened in their existence as a social human being; they feel unable to reach out to others, to be aware of what is happening in their environment, or to discuss and negotiate about the care they receive" (Roets-Merken, et al., 2017).

Interestingly, this study also highlights that, care home residents with dual sensory loss report similar experiences to that of young adults with congenital dual sensory loss. Despite having very different experience of life with dual sensory loss, both groups report feelings of being socially isolated and being out of control of their environment (Roets-Merken, et al., 2017).

It has been observed that loss of hearing and vision among care home residents often goes unnoticed and consequently dementia goes unnoticed and untreated. This impacts negatively on the quality of life of residents who may not be given the correct care and resources to be able to have a good quality of life in care (McGilton, et al., 2016).

As has been stated, dementia can be misdiagnosed or undiagnosed in those with dual sensory loss. Add to this, the fact that residents in care homes are not always screened for sensory loss, it becomes apparent that these two co-morbidities are under-reported. A Canadian qualitative study from 2018 sought to explore the experience nurses had of sensory screening in care home residents and found that respondents were aware of the adequacy of current visual and hearing screening processes and welcomed the development and introduction of these services. They also welcomed the necessary education to make such processes feasible (Wittich, et al., 2018; Höbler, et al., 2018).

Research investigating screening and general health provision for people with dual sensory loss, moreover, has been prominent in the last 5 years, at international level. For example, the first international study on the topic specifically sought the views of health care professionals on the efficacy of the care provided for older people with sensory loss (Leroi, et al., 2019). It was argued that "findings will inform the adaptation of assessments, the development of supportive interventions, and the new provision of services" (Leroi, et al., 2019).

Moreover, in 2021, the first set of international recommendations were published. These recommendations are across disciplines and are intended to hasten:

> "the development of multidisciplinary services and policy to improve the lives of people with dementia and hearing and vision impairment" (Littlejohn, et al., 2021).

These recommendations form extensive work, and it is argued a priority is the detection and diagnosis of dual sensory loss in people with dementia. It is pointed out that the World Health Organisation (WHO) has recently produced a

guide on redesigning care for older people (Thiyagarajan, et al., 2019). These WHO guidelines have “recommended the maintenance of sensory health to preserve physical and mental capacity” and in addition it has been stated that the “recommendation reinforces the need for more specific guidance on hearing and vision impairment” (Littlejohn, et al., 2021).

A qualitative study across three European countries sought the views of people with dual sensory loss and mild to moderate dementia and their carers on the interaction they had received from health care professionals and whether information was accessible for them. Participants reported that assessments were not accessible for them, and the study concluded:

> “…more comprehensive, yet easy to understand, information regarding these linked to conditions and corrective device use is needed. Communication among health care professionals relevant to hearing, vision and cognition needs to be improved” (Wolski, et al., 2019).

Finally, supporting this line of argument, a 2019 survey of health care professionals who work with patients with dual sensory loss and cognitive impairment found that clear assessment guidelines and patient-based solutions were needed (Leroi, et al., 2019).

5. Dual sensory loss - one of the four pillars

While the prime focus of this report is on those with dual sensory loss, it is important to remember that dual sensory loss is one of four types (or pillars) of deafness. Although each of the pillars of deafness is unique, there are areas were issues either run parallel or cross -over and it is helpful to consider dual sensory loss and dementia within this context. Specific resources for those with dual sensory loss and dementia in Scotland are noted also. The 3 other pillars of deafness are:

Deaf, British Sign Language users

People who identify as Deaf, BSL users would have been born deaf or became deaf in early childhood and therefore British Sign Language (BSL) is their first

language. To a greater extent than any of the other categories of deafness, Deaf, BSL users normally identify with a unique Deaf Culture.

Current research and resources on dementia specifically for Deaf, British Sign Language Users in Scotland:

Information on the 'Transforming the Deaf Experience'
BDA

'The Deaf Experience user-friendly toolkit for Deaf people who use BSL and who are living with dementia, their families, carers, and staff who are supporting them'
BDA

The toolkit has recently been supplemented by the outcome of research specific to the experience of Deaf people in care homes. In March 2022 a comprehensive report and guide was produced from the outcome of the research:

'Deaf people with dementia and care homes in Scotland: Navigating effective care home service provision in Scotland for Deaf people with dementia and their families. (March 2022).
BDA

People who are Deafened

People who are Deafened are those who become deaf after learning to speak. Deafness here can be the result of an accident or trauma or might be a side-effect of an illness. People in this category can lose their hearing suddenly or over time and are sometimes described as having "Acquired Profound Hearing Loss" (APHL).

Current research and resources on dementia specifically for people who are Deafened in Scotland:

There are no current information resources on dementia available for people who are deafened, however, the general guide below contains a relevant

section. ’Dementia and Deafness: What you Need to Know’, 2015. This is a useful resource from Deaf Action, which deals with all pillars of deafness.
Deaf Action

People who are Hard of Hearing

The term ‘Hard of Hearing’ is used to describe those whose hearing loss is mild to moderate. In general terms, those who are Hard of Hearing lose their hearing gradually over time. The category includes those with age-related hearing loss and as such potentially most affected by dementia.

Current research and resources on dementia specifically for people who are hard of hearing in Scotland:

There are no current information resources on dementia available specifically for people who are hard of hearing, however, the general guide below contains a relevant section.

’Dementia and Deafness: What you Need to Know’, 2015. This is a useful resource from Deaf Action, which deals with all pillars of deafness.
Deaf Action

Prevalence research carried out by deafscotland in 2019 provides a review of deafness and dementia in Scotland:
Life Changes Trust

Sensory loss – visual

In addition, a relevant set of guidelines has been produced by research undertaken by Sight Scotland. While this addresses visual sensory loss only, again, as with deafness, there will be information that is pertinent to those with dual sensory loss.

“Dementia and Sight Loss: A guide on activities and care of people living with dementia and sight loss” (Sight Scotland, 2019):

6. Modelling prevalence estimates: the main findings

As stated, previous research carried out by deafscotland on prevalence figures for people with dementia who are hard of hearing were modelled (McMenemy & Johnson, 2020). It was evident from this research that it would be possible to build upon the learning and apply a similar methodology to produce likely numbers for those with dual sensory loss and dementia for each of the 32 Local Authorities in Scotland.

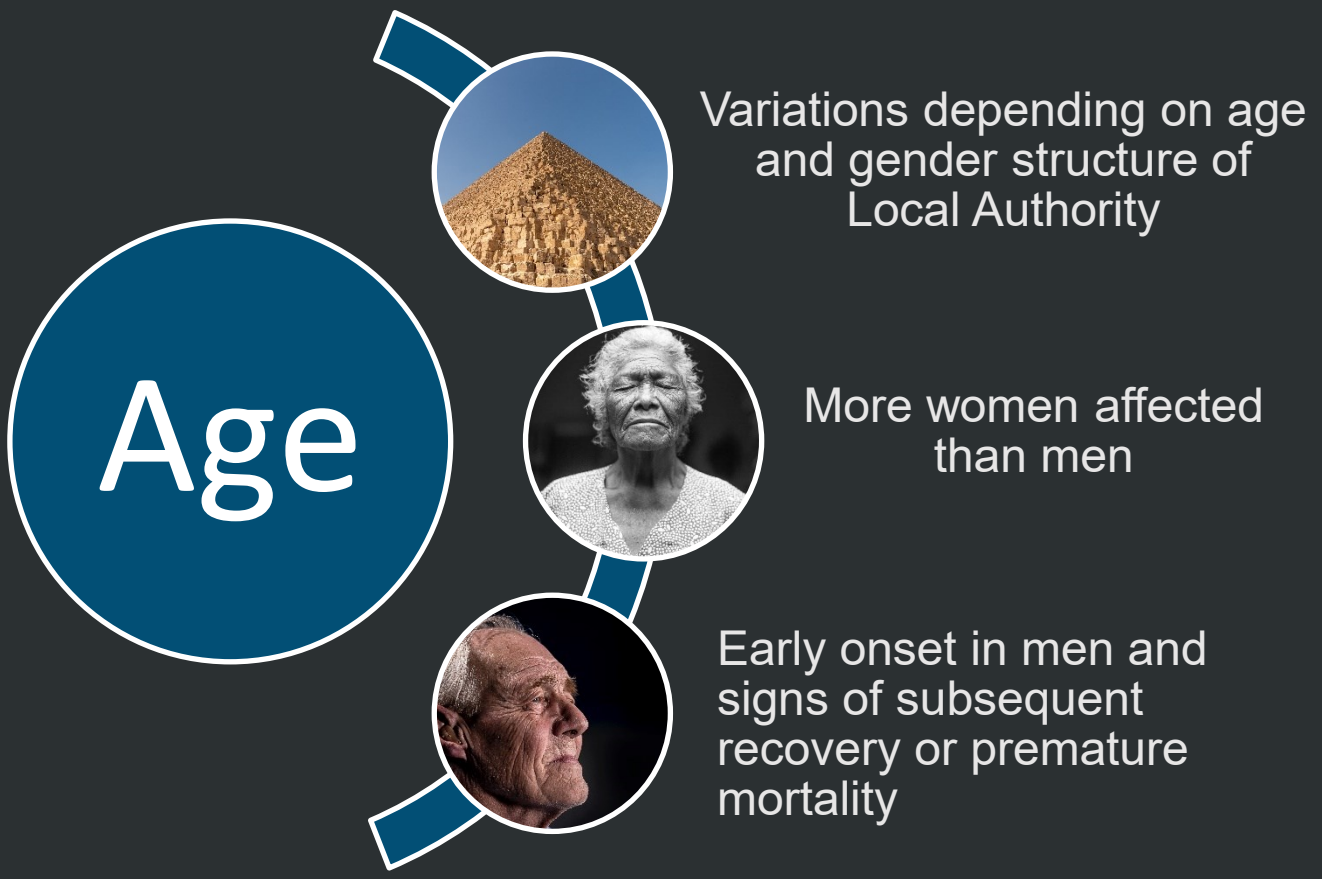


Figure 1 Main Findings

[Figure 1 is a graphic showing the main findings of the research. The image contains one large circle with 'age' written in it, alongside this to the right are three additional smaller circles curving around the larger circle. Each of the circles has a separate image and text.

The top circle has a photo of a pyramid and states the first finding as “variations depending on age and gender structure of Local Authority”; the second circle has an image of an older woman with closed eyes and the second finding states “more women affected than men”; the third circle contains an image of an older man and the third finding states “early onset in men and signs of subsequent recovery or premature mortality”.]

Using a combination of databases, Robertson & Emerson developed an excellent methodology in a 2010 report and provided estimates for people with dual sensory loss for the UK. The prevalence rates in Robertson & Emerson’s work are a comprehensive and robust set of estimates and formed the starting point for the prevalence estimates and modelling within this project. Additionally, (Koesters, et al., 2021) developed a robust framework to model the progression of dementia as people get older for any age structured data set. The combination of both made the results in this report possible. A detailed methodology of the modelling techniques used can be found in Appendix A.

Using this methodology, it was possible to produce detailed age structured prevalence estimates for each Local Authority in Scotland and these are attached as Appendix B.

Summary graphics of the prevalence rates for Scotland are detailed in Figure 2 and Figure 3. These graphics are also shown in Table 1. In depth discussion on prevalence rates can also be found in Appendix B.

Table 1 Estimates of numbers of people with dual sensory loss and dementia in Scottish Local Authorities

Council	female	male	both
Aberdeen City	66	39	105
Aberdeenshire	84	55	139
Angus	53	30	83
Argyll and Bute	37	23	60
City of Edinburgh	165	94	259
Clackmannanshire	14	10	24
Dumfries and Galloway	63	43	106
Dundee City	51	28	79
East Ayrshire	38	24	62
East Dunbartonshire	50	32	82
East Lothian	38	24	62
East Renfrewshire	43	24	67
Falkirk	48	32	80
Fife	132	84	216
Glasgow City	159	78	237
Highland	94	61	155
Inverclyde	30	16	46
Midlothian	27	19	46
Moray	38	25	63
Na h-Eileanan Siar	13	8	21
North Ayrshire	50	30	80
North Lanarkshire	87	51	138
Orkney Islands	10	6	16
Perth and Kinross	70	47	117
Renfrewshire	57	35	92
Scottish Borders	47	30	77
Shetland Islands	7	6	13
South Ayrshire	52	32	84
South Lanarkshire	107	64	171
Stirling	34	20	54
West Dunbartonshire	26	15	41
West Lothian	45	31	76
Sum:	1835	1116	2951

[**Table 1** Lists the numbers of people with dual sensory loss and dementia in Scottish Local Authorities. Numbers are displayed in a separate row for each Local Authority, sorted by

gender and a sum total provided for each Authority. The table shows that: Aberdeen City has 66 female, 39 male and these sum to 105 people with dual sensory loss and dementia. Aberdeenshire has 84 female, 55 male and these sum to 139 people with dual sensory loss and dementia. Angus has 53 female, 30 male and these sum to 83 people with dual sensory loss and dementia. Argyll and Bute have 37 female, 23 male and these sum to 60 people with dual sensory loss and dementia. City of Edinburgh has 165 female, 94 male and these sum to 259 people with dual sensory loss and dementia. Clackmannanshire has 14 female, 10 male and these sum to 24 people with dual sensory loss and dementia. Dumfries and Galloway have 63 female, 43 male and these sum to 106 people with dual sensory loss and dementia. Dundee City has 51 female, 28 male and these sum to 79 people with dual sensory loss and dementia. East Ayrshire has 38 female, 24 male and these sum to 62 people with dual sensory loss and dementia. East Dunbartonshire has 50 female, 32 male and these sum to 82 people with dual sensory loss and dementia. East Lothian has 38 female, 24 male and these sum to 62 people with dual sensory loss and dementia. East Renfrewshire has 43 female, 24 male and these sum to 67 people with dual sensory loss and dementia. Falkirk has 48 female, 32 male and these sum to 80 people with dual sensory loss and dementia. Fife has 132 female, 84 male and these sum to 216 people with dual sensory loss and dementia. Glasgow City has 159 female, 78 male and these sum to 237 people with dual sensory loss and dementia. Highland has 94 female, 61 male and these sum to 155 people with dual sensory loss and dementia. Inverclyde has 30 female, 16 male and these sum to 46 people with dual sensory loss and dementia. Midlothian has 27 female, 19 male and these sum to 46 people with dual sensory loss and dementia. Moray has 38 female, 25 male and these sum to 63 people with dual sensory loss and dementia. Na h-Eileanan Siar has 13 female, 8 male and these sum to 21 people with dual sensory loss and dementia. North Ayrshire has 50 female, 30 male and these sum to 80 people with dual sensory loss and dementia. North Lanarkshire has 87 female, 51 male and these sum to 138 people with dual sensory loss and dementia. Orkney Islands has 10 female, 6 male and these sum to 16 people with dual sensory loss and dementia. Perth and Kinross have 70 female, 47 male and these sum to 117 people with dual sensory loss and dementia. Renfrewshire has 57 female, 35 male and these sum to 92 people with dual sensory loss and dementia. Scottish Borders has 47 female, 30 male and these sum to 77 people with dual sensory loss and dementia. Shetland Islands has 7 female, 6 male and these sum to 13 people with dual sensory loss and dementia. South Ayrshire has 52 female, 32 male and these sum to 84 people with dual sensory loss and dementia. South Lanarkshire has 107 female, 64 male and these sum to 171 people with dual sensory loss and dementia. Stirling has 34 female, 20 male and these sum to 54 people with dual sensory loss and dementia. West Dunbartonshire has 26 female, 15 male and these sum to 41 people with dual sensory loss and dementia. West Lothian has 45 female, 31 male and these sum to 76 people with dual sensory loss and dementia. All of these sum to 1835 men, 1116 women and give a total prevalence figure of 2951 people with dual sensory loss and dementia in Scotland.]

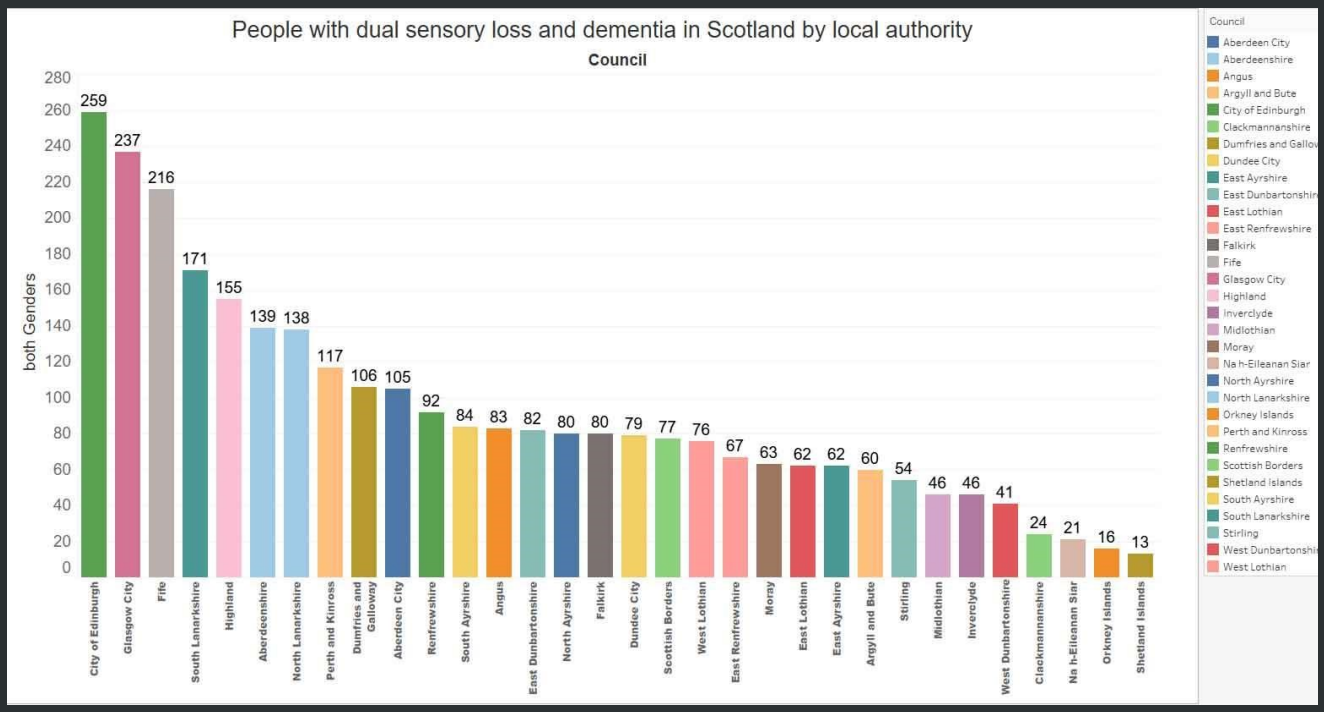


Figure 2 Estimates of total numbers of people with dual sensory loss and dementia in Scottish Local Authorities

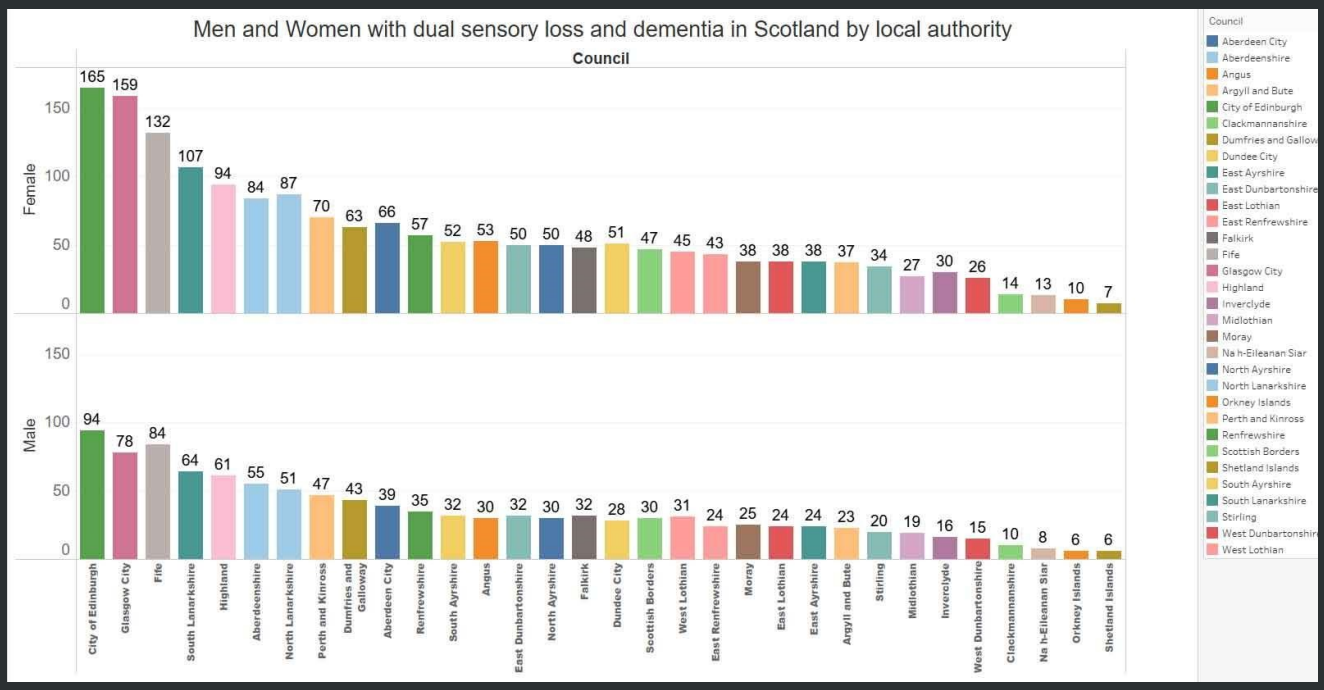


Figure 3 Estimates of number of people with dual sensory loss and dementia in Scottish Local Authorities

[Figure 2 **is a graphic of the information contained in Table 1, giving prevalence rates for those with sensory loss and dementia in each Local Authority in Scotland. This figure gives the overall numbers and is not broken down by gender.]**

[Figure 3 **is a graphic of the information contained in Table 1, giving prevalence rates for those with sensory loss and dementia in each Local Authority in Scotland. Here the numbers for each Local Authority are sorted by gender.]**

7. Conclusion

The main barrier to gathering data on those with dual sensory loss and dementia is the lack of consensus in the definition. Definition is of pivotal importance. Lack of a robust definition hinders identification of cases and allows people to fall through the net. Addressing this, (Minhas, et al., 2022) set out a list of recommendations needed to ensure research on dual sensory loss is fit for purpose:

> "It is recommended that future research studies about individuals with deafblindness include coordinated data-collection tools such as (a) standardized definitions of deafblindness or dual-sensory loss; (b) severity levels of visual and hearing impairments; (c) level of sensory functioning in relation to access to information, communication, and mobility; (d) age of onset of deafblindness or dual-sensory loss; and (e) language and communication ability at the onset of deafblindness or dual sensory loss" (Minhas, et al., 2022).

Alongside this, it is evident that screening and diagnostic processes need to have a multi-agency approach, with data being shared across the sectors. In terms of screening and diagnosis also, it is imperative that identification of dual sensory loss is considered so that misdiagnosis of dementia is lessened.

Dual sensory screening processes need to be nuanced. This will ensure cases are identified as early as possible, resulting in optimum and timely service provision.

Diagnostic technology in relation to dementia must take into consideration that dual sensory loss may provide clinicians with skewed results. As such, diagnostic procedure must be nuanced and adapted to suit individual need.

'Social isolation' is a term that has become well-known across society because of COVID-19. During the pandemic, measures put in place to protect wider society caused distress to those with dual sensory loss. From masks which made it impossible to lip read; the 2-metre rule for social distancing rendering hearing aids useless or the loneliness and isolation caused by shielding. All measures made communication impossible, resulting in exclusion and isolation. There can be no doubt that post-pandemic society will have a greater awareness of the term 'social isolation'. Those with sensory loss experience social isolation as part of their daily lives.

Individuals with dual sensory loss are in danger of being socially isolated due to the many communication barriers that sensory loss brings with it. As with mid-life hearing loss, social isolation is a potentially modifiable causal factor in dementia. The relevance of the need to tackle this social isolation is clear.

In summation, it is evident that individuals with sensory loss and dementia and the people who care for them need to be able to access several health and social care services – both specialist and more accessible mainstream services and support. But, as has been argued – how can this be done effectively and efficiently if the numbers of these individuals are not known?

In this research, modelling has been added to existing prevalence work to obtain robust estimates for those with dual sensory loss and dementia for all 32 Councils in Scotland. It is hoped that these figures can assist with service provision, both now and in the future.

Future Research:

Building upon the regional prevalence research for Scotland outlined in this report, a comparative study with Norway would enrich learning and add to wider understanding in the field. The two countries are similar in population size, are in the same part of the world and have the same access to immunisations, MMR vaccines etc.

In addition, as stated, Norway has a definition for deafblindness, has identification teams and a healthcare infrastructure that recognises deafblindness. At present Scotland does not. To what extent, then, do the prevalence rates of the two countries compare?

There is the potential for a strong cross-national comparative study that would add to and strengthen current dual sensory loss and dementia evidence base.

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9. Appendices

A: Modelling Detail
B: Dual Sensory Loss and Dementia in Scotland Individual Local Authorities report
C: Dual Sensory Loss in Scotland Individual Local Authorities report

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