**Co-producing a boardgame to learn and engage about dementia inequalities: First impacts on knowledge in the general population**

**Clarissa Giebel1,2,\*, Kerry Hanna3, Hilary Tetlow2,4, Mark Gabbay1,2, Jacqui Cannon2,5**

1 Department of Primary Care & Mental Health, University of Liverpool, UK

2 NIHR Applied Research Collaboration North West Coast, Liverpool, UK

3 School of Health Sciences, University of Liverpool, UK

4 SURF Liverpool, UK

5 Lewy Body Society, Wigan, UK

*Correspondence should be addressed to:* Clarissa Giebel, University of Liverpool, Email: Clarissa.giebel@liverpool.ac.uk

**Abstract**

**Background:** Receiving and accessing care after a diagnosis of dementia, both for the person and their carer, are fraught with inequalities. The aim of this public engagement activity was to co-produce a boardgame about dementia inequalities to facilitate learning, dialogue and educate about different barriers, and facilitators, to diagnosis and care, and to test the game’s impact on dementia knowledge with the general public.

**Methods:** Two virtual and two face-to-face workshops with people with dementia, unpaid carers, health and social care professionals, and Third Sector representatives were held between October 2022 and June 2023. Virtual workshops involved discussions of inequalities and how a boardgame may feature inequalities. The first face-to-face workshop was split into the same activities, aided by outcomes from workshops 1 and 2. Workshop 4 attendees tested the prototype. The impact of the game on knowledge about dementia and inequalities was tested at a Game Play Workshop in October 2023.

**Results:** Forty stakeholders attended four workshops. Workshops provided step-by-step thoughts on how the game could be designed or modified. The final game, prototype tested in Workshop 4, consists of a one-sided, two-half board depicting the pre-diagnosis process (left half) and post-diagnosis process (right half). Fifty-two members of the general public participated in the Game Play Workshop, which led to significant improvements in knowledge about dementia (p<.001) and inequalities (p<.001).

**Discussion:** The game can be used to improve knowledge about dementia inequalities for health and social care professionals, carers, people living with dementia, decision makers, and the general public.

**Patient or Public Contribution:** This engagement activity fully involved people with dementia, unpaid carers, health and social care professionals, and Third Sector representatives throughout, with two unpaid carers as public advisers on the team.

*Keywords: dementia; inequalities; game; social care; diagnosis*

**Introduction**

With an estimated 55 million people living with dementia worldwide (WHO, 2022), not everyone receives equal access to a diagnosis, or to care thereafter. The majority of people face barriers in accessing a diagnosis, and are affected by further diverse inequalities in getting the care they need (ADI, 2022; Alzheimer’s Society, 2022).

 Receiving a diagnosis of dementia can be challenging, and is affected by many factors, including education, culture, stigma, GP knowledge, age, and dementia subtype (Burkinshaw et al., 2023; Mukadam et al., 2011; Parker et al., 2020). Culture and understanding of dementia can be significant barriers, especially among people from minority ethnic backgrounds in high-income countries and people residing in low- and middle-income countries (LMICs) (ADI, 2022; Johnston et al., 2020). Dementia is often heavily stigmatised within communities, and adding to that a lack of resources for adequate health care, people living in LMICs face particularly serious barriers in the path to diagnosis (Seeher et al., 2022). Regardless of where people live, being aged below 65 and/or experiencing symptoms that are part of a rarer subtype of dementia, such as behavioural-variant fronto-temporal dementia, Lewy body dementia, semantic dementia, or Posterior Cortical Atrophy, makes an individual less likely to receive a diagnosis, or receive the diagnosis belatedly compared to those aged above 65 and experiencing symptoms of the most common form of dementia – Alzheimer’s Disease (Bentley et al., 2021). This is linked to a lack of GP awareness of the symptoms, with GPs often failing recognising that someone in their 30s may experience symptoms of dementia (Burkinshaw et al., 2023).

Where people do receive a diagnosis, the journey afterwards is often also characterised by various hurdles. These can include inequalities due to dementia subtype, living location, geographical differences in service provisions (‘postcode lottery’, whereby residents in adjacent postcodes or nearby streets receive different access to care due to catchment areas), availability of an unpaid carer, financial background, education, knowledge of available services, and many more (Giebel et al., 2021a, 2021b, 2023a; Kenning et al., 2017). Accessing post-diagnostic support, such as day care, respite care, peer support groups, and paid home care, can be facilitated by financial support from local government social care services in the UK and is means tested. However, many people with dementia and their carers have to pay for care themselves, or supplement their limited free care by self-funding, as a recent 3-UK-nation (England, Wales, Northern Ireland) survey on the impact of the cost of living crisis on people with dementia’s ability to fund social care and support services has also highlighted (Giebel et al., 2023b). Whilst people with dementia and their carers may know they need support, many lack the knowledge of available and existing services to access within the community (Stephan et al., 2018). Having a link person, or Dementia Care Navigator, can help facilitate improved access to care, a service which is strongly embedded within the Dutch care system for example (Giebel et al., 2021a). Having a link-person that is culturally sensitive may also circumnavigate the substantial barriers that those from minority ethnic backgrounds are facing in trying to find culturally suitable services (Nielsen et al., 2021). A link-person may also help those with Young-Onset dementia and those with rarer subtypes of dementia, who face additional barriers to accessing care (Cations et al., 2017; Giebel et al., 2021c). Thus, inequalities both for getting a diagnosis, and for living with the condition, are plentiful, yet still little addressed in practice, leading to different health and well-being outcomes for people with dementia and their families depending on their background characteristics, as well as system-level factors.

Whilst standard interventions can try and address inequalities in dementia diagnosis and care as much as possible within continued social care budget restraints, a boardgame may raise awareness among professionals (both in training and qualified), the public, carers and people living with dementia, about these issues, generate discussion and enable sharing knowledge about barriers, facilitators and solutions. Previous boardgames into dementia have specifically looked at mindful storytelling (Niedderer et al., 2022) and activities and storytelling related to dementia for people with dementia (Branco et al., 2017), whilst one digital game successfully raised general awareness and perception of dementia (Carter et al., 2021). Niedderer et al. (2022) co-produced a boardgame focusing on using mindful life-storytelling in dementia to support well-being and quality of life. In the game, players (people with dementia) role a dice and pick up cards with mindful questions, to reflect on different life experiences and to try and adopt a positive outlook on life. The final game was qualitatively evaluated with 50 people with dementia and 19 carers across four countries, evidencing the game’s facilitation of meaningful social interaction, and increased acceptance of the diagnosis. In addition, Branco et al. (2017) had co-produced a single board game as a co-production and participatory activity with people with dementia in two different care facilities and their families. It is unclear however what the researchers meant by ‘care facilities’. The aim of the activity was to generate activities to engage and socialise in storytelling between the family and the person with dementia, about activities taking place at the care facilities. These activities could be personalised. This game was specific to the two care institutions and the people with dementia being cared for, with the aim of replicating some of the activities engaged with at the facilities at home with the family carer. The game is based on the goose game structure, with each field representing an activity. Players need to pick up cards which provide further details on an activity of reflection. No information was provided on the number of families and people with dementia who engaged in the co-production. Thus, whilst limited, very topic-specific and personalised boardgames have been co-developed in the field of dementia, none has focused on the full trajectory of dementia (from pre- to post-diagnosis), associated inequalities, and potential facilitators to overcoming those. A game can take the crucial step from research evidence to implementation and dissemination, and is thus a very suitable format to translate knowledge in this topic area to raise awareness of dementia and associated inequalities.

The aim of this paper was to detail the methods of co-producing a boardgame into dementia inequalities via public engagement, and to test the impact of the game on knowledge about dementia and associated inequalities in members of the general public. This approach can be used for other research topics and evidence collections to widen impact and generate an engaging format of dissemination.

**Methods**

**Co-production workshops and game development**

A total of four co-production public engagement workshops were held to co-design the Dementia Inequalities Game, to translate research evidence to implementation. Figure 1 depicts the process of the game development and co-production workshops at each stage. Hosting both virtual and face-to-face workshops enabled wider access to participation in the co-production and public engagement of the game development, with some unpaid carers for example having to care for their relative at home and thus unable to attend in person events.

 Eligible attendees included people living with dementia, current and former unpaid carers for someone with dementia, health and social care providers, Third Sector and Local Government social care representatives. Each workshop had different attendees, and co-production and public engagement workshops were purposefully mixed to ensure a wider representation of voices and experiences. Attendees were recruited via existing networks with NHS, social care, and Third Sector organisations, the Liverpool Dementia & Ageing Research Forum, and social media. Attendees were reimbursed with a £25 shopping voucher for their time.

 The first two 2-hour co-production workshops (October 2022, January 2023) were held virtually on Zoom, involving (1) introductions of attendees and facilitators; (2) discussion of inequalities in dementia; and (3) discussion of ideas for how a board game could potentially look and what it should entail. For both discussion points, a Jamboard© (digital interactive whiteboard) was used so that each attendee could either add their thoughts or the facilitator could add these during ongoing discussions. Using this approach enabled the generation of various ideas without being restricted to a limit of suggestions.

In between the virtual and face-to-face workshops, the team produced print outs of all barriers on coloured cards, distinguished by colour into pre- and post-diagnosis. The team also produced a basic sketch design of the boardgame as suggested by attendees from workshop 1 and 2 for attendees to draw on, without having had a pre-conceived idea of what a game should look like.

At workshop 3 (March 2023), attendees were seated in group tables, each facilitated by one or two research team members. Attendees were given two activities: (1) to prioritise different barriers for pre- and post-diagnosis; and (2) in discussion, drawing onto the printed out boardgame sketches how the basic structure of the game could be advanced. Each activity lasted approximately 50 minutes, with times for introductions and a refreshment break in between. All facilitators took notes of discussions at their respective group table, and summarised the discussion points at the end for the whole workshop.

After workshop 3, the research team fed the workshop discussions and suggestions from the sketch drawings onto the electronic board game design. A game developer (Focus Games) was employed to formally design the board game, and to produce four copies of a prototype.

At workshop 4 (June 2023), people living with dementia, unpaid carers, health and social care professionals, PhD students, academics, and academic administrators played the prototype of the game and provided feedback. Attendees were grouped into three groups, with each consisting of between four to five players.

**Game Play Workshop**

In collaboration with the House of Memories, a Liverpool-based Third Sector organisation providing training and information sessions about dementia and how to use memory objects to people with dementia, unpaid carers, and health and social care professionals, we held a 6-hour open door and pre-book game play workshop at the Museum of Liverpool. 10 games were set out on tables available to play for any member of the general public aged 18+. Attendees were invited via a mail out and social media via the public Liverpool Dementia & Ageing Research Forum and the House of Memories, and approached in and outside the museum with leaflets about the game play workshop. Attendees were provided with a hot drink during the workshop. If interested, attendees were provided with a study information sheet, study consent form, and a pre- and post-game play dementia knowledge questionnaire. This brief 2-sided questionnaire (see Appendix 1) was co-developed with both public advisers to have a short evaluation of the impact of game play on knowledge about dementia and associated inequalities. Pre- and post-game play knowledge about dementia (Question 1) and dementia inequalities (Question 2) were rated on a Likert Scale ranging from ‘1’ (poor) to ‘5’ (very good).

 Attendees were able to play within their own social group, or could join other attendees. The research team was available throughout the workshop and could answer questions. However, to mimic the impact of the game play in non-evaluation settings, the team provided no addition instructions or guidance, but left attendees to read through the game instructions themselves.

We received ethical approval from the [Ref: 12878] prior to conducting the Game Play Workshop.

**Analysis of game play workshop knowledge questionnaire data**

We conducted paired samples t-tests to compare potential significant differences in pre- and post-game questions on dementia knowledge (Question 1) and dementia inequalities (Question 2).

**Public involvement within the team**

Two unpaid carers for former relatives with dementia (JC, HT), both of whom are running their own dementia Third Sector organisation, were part of the research team. Both carers contributed to all aspects of the project, including designing and co-facilitating the co-production workshops, designing the boardgame based on workshop suggestions and feedback, as well as dissemination.

**Results**

**Co-production workshops**

Forty people with dementia, unpaid carers, health and social care professionals, and Third Sector representatives, as well as academics, PhD students, and academic administrators (Workshop 4 only) participated across the four workshops (n1=7; n2=3; n3=18; n4=12). Workshops 1 and 2 generated (1) different barriers and facilitators experienced when trying to access dementia care services; and (2) first ideas about how a boardgame should capture these. Across the workshops, it emerged that only focusing on post-diagnostic inequalities failed to include a key part of the dementia trajectory, and associated inequalities – namely receiving a diagnosis. Thus, a key decision emerging from the workshops was to create a double-sided boardgame, with one side representing pre-diagnosis, and one the other side representing post-diagnosis. Table 1 lists all identified barriers pre- and post-diagnosis.

The fourth workshop was conducted after the prototype had been designed, and focused on attendees providing feedback on the game and gaming experiences. Attendees suggested to change the dice colour to red to stand out more, add a ‘roll-again’ option when rolling a six on the dice, and provide further clarifications for the game instructions. Clinicians suggested to remove the activities element from the cards as they were too distracting, and the activities pre-diagnosis might feel too similar to a cognitive assessment for people living with dementia. However, all other players enjoyed the activities. As a result of this feedback, we have added a sentence at the bottom of each Activity card stating that if a player does not wish to engage in the activity, they can take a Question card instead.

**[Table 1]**

**The game**

**Overall concept**

Based on existing evidence from the research team and from further afield, and based on the two-step co-production process, the boardgame incorporates barriers and facilitators to receiving a diagnosis and post-diagnostic dementia care on a *Snake and Ladder* style format. The game comprises of two halves, with one half focusing on the diagnosis process, and the other half on post-diagnostic care. On the left side of the game (diagnosis), the end point and goal of the game is to receive a diagnosis. On the right side of the game (post-diagnosis), the starting point is the diagnosis, and the end point depicts living well with dementia. The game is designed for 2-4 players or teams, who in turn roll a dice to move forward on the board. When a player rolls a six, they can roll the dice again.

People depicted on the game graphics are purposefully diverse and inclusive, including gender, age, and ethnic background, to address some of the underlying characteristics that can lead to inequalities in dementia. Figure 2 shows a visual of the board game and the cards.

***Inequalities embedded within board game***

Different barriers to dementia diagnosis and care were discussed and generated with workshop attendees, feeding into different inequality cards for the game. If a player moves onto a field indicated with a ‘scale’, an opposing player (or team) reads out the next card in the relevant stack. Each card includes either a barrier or facilitator to care, and asks the player to either move several steps forward (facilitator) or backwards (barrier).

***Questions and Activities***

Players can move onto fields where they are asked to pick up a ‘Question or Activity’ card. When a player chooses the correct answer from the three options offered, or undertakes the activity, they move forward one step. If they answer the question incorrectly, they stay on their current game spot.

For the pre-diagnosis side of the game, activities were derived from memory assessment tools used in the diagnosis process of dementia, such as the Mini-Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975), the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005), and the Addenbrooke’s Cognitive Examination III (Hsieh et al., 2013). For example, players might be asked to remember 5 digits. On the post-diagnosis board game side, activities focused on engaging in activities that are shown to improve well-being in dementia and linked to delayed symptom deterioration. For example, players might be asked to do a wall-sit, thus referring to physical fitness and activity in general.

**Impact of the game on knowledge about dementia and inequalities**

Fifty-seven members of the general public participated in the game play workshop, with five attendees not completing the post-game questionnaire or handing in their questionnaire. Thus, 52 members of the general public aged 18+ participated and completed the questionnaire. Participants were on average 46 years old (+/-18) [Range 19-83], and were predominantly female (n=30; 57.7%).

 Paired samples t-test showed a significant difference in pre- and post-game play knowledge about dementia [t(51)=-3.470, p<.001], with a pre-game mean score of 3.04 (+/-1.15) and post-game of 3.5 (+/-0.9). Paired samples t-test also showed a significant difference in pre- and post-game knowledge about inequalities in dementia [t(50)=-6.268, p<.001], with a pre-game mean score of 2.39 (+/-1.08) and post-game of 3.35 (+/-1.07).Thus, playing the game improved both knowledge on dementia, and dementia inequalities.

**Discussion**

This is the first game to focus on inequalities in dementia diagnosis and care, which has been co-produced at all stages of its development. The final game version includes content demonstrating various inequalities both in the pre-diagnosis and post-diagnosis stage, as well as additional questions to raise general awareness about dementia. The game can also be seen as a boundary object, prompting discussions about health inequalities, associated stigma, barriers and solutions to overcome them along the dementia journey. Playing the game can successfully improve knowledge about dementia and associated inequalities.

Without any previous co-produced game on inequalities in dementia, this public engagement activity and quantitative evaluation of the Dementia Inequalities Game has shown that the game fills a necessary and innovative gap to educate about the topic and reach non-academic stakeholders (including health and social care professionals, students, people affected by dementia) and the general public. This game has translated a substantial evidence base on dementia inequalities, via in-depth co-production, and this paper provides a framework for translating evidence in other research areas into a game. Previous games focused on mindful storytelling (Niedderer et al., 2022) and activities and storytelling related to dementia for people with dementia (Branco et al., 2017), and our game provides an informative and engaging approach on real-life barriers to diagnosis and care different to the existing developed games. Future work needs to focus on co-producing a theory of change, to explore how engaging with the Dementia Inequalities Game can impact on knowledge and potential care practices in health and social care professionals. This can be guided by delivering game play workshops to professionals with key principles identified as part of dementia education programmes by Phillipson et al. (2016). These include using simple and clear messages and outcomes for the game and providing incentives to playing the game. These have been identified for healthcare professionals, based on using Knowledge Translation as a conceptual framework for general learning. However, these principles could also be applied to social care professionals (including those working in home care, day care, respite care, and residential care). Given the severe restraints on many health and social care professionals’ time and high job demands, conducting a 1-hour educational, and social, game play workshop, can provide an important opportunity to learn and socialise with peers in the work place environment, without the need to travel to take individual training courses.

**Conclusion**

This is the first fully co-produced game on dementia inequalities, with early evidence from the general public indicating its successful impact on improving knowledge about dementia and associated inequalities. The next step will be to run a full evaluation of the impact of the game play on knowledge about dementia and associated inequalities with health and social care professionals and students, possibly with more in-depth dementia knowledge questionnaires such as the Dementia Knowledge Assessment Scale (Annear et al., 2017), which was considered too lengthy for this pilot general public evaluation of a drop-in game play workshop. It is also important to assess whether engaging in the game may change access to dementia diagnosis and care in the long-term for people living with dementia and their carers and can lead to changes to care delivery in the health and social care workforce. In future, the Dementia Inequalities Game has the potential to be modified to different countries or regions across the world, to be used as an awareness raising and education tool to overcome stigma and improve knowledge.

**Conflicts of interest**

HT is the organiser of SURF Liverpool, which funded the fourth workshop.

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**Ethics statement**

We received University of Liverpool ethics approval [REF: 12878] prior to the game play workshop.

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**Table 1. List of identified and discussed barriers pre- and post-diagnosis**

|  |  |
| --- | --- |
| **Barriers pre-diagnosis** | **Barriers post-diagnosis** |
| Unable to use digital forms of communication/support | Unsuitable support groups/activities |
| sensory impairments preventing access | Care home location |
| Lack of funding (local area) | Unable to use digital forms of communication/support |
| Staff are not familiar/trained in dementia diagnosis (e.g. rare dementias) | sensory impairments preventing access |
| Cultural / language barrier | Lack of funding (local area) |
| Stigma | Staff are not equipped/trained/motivated |
| Post-code lottery e.g. continuing healthcare awarded to some people in particular areas and not in others | Legalities e.g. power of attorney  |
| Unable to accept diagnosis  | Cultural / language barrier |
| Mobility /transport issues | Stigma |
| The signs/symptoms they experience (could lead to misdiagnosis) | Post-code lottery e.g.continuing healthcare awarded to some people in particular areas and not in others |
| Decision not to diagnose | Lack of information provided when diagnosed |
| Lack of help seeking behaviour (reluctance in seeing a professional/getting a diagnosis) | Unaware that you are a “carer” |
| Rarer dementia subtype diagnosis | Anger/distressed caused by carers coming in to home |
| Young-onset dementia (Age) | Difficulties getting care funding from care sector and local authority) |
| Lack of knowledge about symptomatology | Mobility /transport issues |
|  | Lack of support from family  |
|  | High costs associated with care |
|  | Too much information |
|  | Rarer dementia subtype diagnosis |
|  | Young-onset dementia (Age) |
|  | Lack of knowledge about symptomatology |
|  | Not having an unpaid carer (living alone) |
|  | Lack of link worker (Dementia Care Navigator) |
|  | Lack of personal wealth |

**Figure 1. The Dementia Inequalities Game – Process of game development**

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**Figure 2. The Dementia Inequalities Game**

**Appendix I. Dementia knowledge questionnaire**

**Dementia Inequalities Game Evaluation**

**PRE-GAME Questionnaire**

(please circle your responses and write in the provided text boxes)

1. How would you rate your knowledge about dementia? (1 – poor 🡪 5 – very good)

1 2 3 4 5

1. How would you rate your knowledge about inequalities in dementia?

1 2 3 4 5

1. Do you know how many people live with dementia in the UK?
2. Do you know the most common type of dementia?

**POST-GAME Questionnaire**

(please circle your responses and write in the provided text boxes)

1. How would you rate your knowledge about dementia?

1 2 3 4 5

1. How would you rate your knowledge about inequalities in dementia?
2. 2 3 4 5
3. Do you know how many people live with dementia in the UK?
4. Do you know the most common type of dementia?
5. What have you learned from playing this game?
6. Will you make any changes as a result of your learning from this game? This could be in your clinical practice or daily life.