Report on a problem studied in the N-CODE Study Group March 2023

“re-writing loneliness in dementia”

IMPROVING THE STORY OF DEMENTIA’S FUTURE THROUGH MACHINE LEARNING

(Technology to Reduce Loneliness in People with Dementia: Digital and Distance Interactions)

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Abstract

The number of people living with dementia is increasing, so is the number of people with dementia (PwD) living with loneliness (1,2). Being lonely has significant detrimental impacts on mental and physical health (3,4). Face-to-face interventions to reduce loneliness in PwD are effective and well received but not everyone can access them, and some people want other options alongside face-to-face groups (5–9). Technological interventions have had a mixed reception, interventions that were personalised had the best efficacy, there is a gap in the research for technologies aimed at people living alone (10).

The aim of the study group is to develop a technology that could reduce loneliness in people with dementia. The technology needs to be personalised to the individual and to be accessible to people who live alone without someone to help them use the technology.

The initial step to achieve this is to develop a method of the technology assessing for loneliness, across different levels of cognitive impairment and intersectionality. We have demonstrated a proof of concept that loneliness could be measured from textual data. To develop an accessible and effective intervention a co-design methodology is proposed, a rapid review of the literature has found Experience Based Co-Design is a validated and safe method of co-deign with vulnerable groups.

An overview of the mathematical models is described, and an adapted form of Experience Based Co-Design explored to produce a project plan. The outcome of the project will be a technological intervention that can adapt to an individual's changing loneliness, cognition and interests as they travel through their dementia story, reducing their levels of loneliness.

1 Introduction

Dementia and loneliness

It is estimated that there are 885,000 people in the UK living with dementia; this is projected to increase to over 1.5 million people by 2040 (1). People with dementia (PwD) are a diverse group of people linked by experiencing a condition that has significant effects on physical, mental, and social health (3,11). Having dementia increases the risk of experiencing loneliness, with 38% of respondents to an Alzheimer's Society survey reporting feelings of loneliness (2,12); this has been exacerbated by the pandemic (13,14).

The impact of unaddressed loneliness

A PwD experiencing loneliness has negative impacts on their health, their carers and is associated with increased economic cost. Impacts on the individual range from increased risk of depression, increased risk of physical health conditions and negative impact on cognition (3). Loneliness is also associated with increased all-cause mortality (4). The increased risk of co-morbidity confounds care-giver burden, increasing risk of carer stress, depression, and anxiety symptoms (15,16). Although there have been no specific studies of the economic cost of loneliness in PwD, loneliness in general has been found to be associated with excess health care costs. Interventions to address loneliness are likely to be cost saving, particularly those that increase social contact (17).

Existing interventions to reduce loneliness

Face-to-face and technological interventions have been developed to reduce loneliness in PwD. Voluntary social groups, such as memory cafés, have successfully increased opportunities for people with dementia to socialise and therefore reduce loneliness (5–7). However, barriers to face-to-face groups include accessibility, transport links and physical co-morbidities; covid highlighted the need to have alternative means of meeting (8,9). Those who can attend face-to-face meetings might benefit from other interventions that they can access alongside existing provision.

Furthermore, some PwD express a preference for groups with people who share their interests, not solely a dementia diagnosis. As a society we are increasingly used to having personalised experiences; as one PPI attendee commented "I wouldn't have wanted to socialise with these people before I had dementia so why would I want to now?"

Technology has been considered a possible solution to overcome these barriers. Efficacy in reducing loneliness has been mixed (10). In a scoping review of 73 interventions found, 64 involved face-to-face interactions with other people in the same place and only six facilitating distance interaction. This does not target those who are more socially isolated; social isolation has been found to be a risk factor for loneliness (18). Personalisation of the technological intervention was found to improve acceptability and efficacy. Less than half of the papers found included subjective feedback directly from the PwD who used the technology (10). Another limitation is that many interventions have focused on those with milder cognitive impairment, loneliness is known to affect PwD independently of dementia stage (18).

There is not currently an intervention, used independently by PwD, that can be personalised to interest, level of loneliness and severity of cognitive impairment.

2 Description of the problem

Based on the literature there are several problems that need to be overcome to allow PwD to benefit from a technology to reduce loneliness.

Accessibility and Acceptability

Current technological interventions frequently require a facilitator to assist PwD to access them. Even those technologies which focus on interaction with technology alone need a facilitator to set the technology up and ensure the PwD can access the intervention.

Existing research in this area frequently fails to ask PwD if they find the technology acceptable or would be likely to use it in their day-to-day life (10). There is no data available about how intersectionality of the user groups affects accessibility. This potentially limits the impact of these technologies if there were to be rolled out, either commercially or by health and social care.

Personalisation

Current technological interventions for loneliness have improved acceptability and efficacy when they are personalised to the PwD's interests, life-story, and situation. This can be done by a carer or facilitator and allows, for example, a tablet-based intervention to show media that is personally relevant to the PwD. However, this relies on a facilitator to set up the technology. It also does not take account of how dementia progresses over time. Dementia causes anterograde and retrograde amnesia. The retrograde amnesia causes recent memories to be lost first, and then more distant memories; this results in the person 'rolling back in time'. Interests, experiences, and societal reference points change over history and as a person ages.

Adaptable to level of loneliness

Perception of loneliness can change day-to-day and over the course of the day depending on numerous biological, psychological, and social variables. The intervention that people may find most beneficial to reduce loneliness may depend on their level of loneliness at that time. We do not have evidence for this. Machine learning (ML) procedures can develop predictive algorithms able to identify the most probable reason based on information for one individual person (supervised ML), or by identifying possible distinct subgroups from a population (unsupervised ML)(19). However, there is currently no validated classifier to identify loneliness in PwD. There are standardised assessments available (20), these involve the PwD answering questions about loneliness which may be distressing and leads to a point-in-time rather than continuous assessment. The benefit of having on-going assessment based on normal speech is that assessment is integrated in the intervention. Work towards this has already been started, but mostly concentrating on older adults, rather than PwD.

Adaptable to level of cognitive impairment

As a person's dementia progresses over time, symptoms in the different cognitive and non-cognitive domains change. This will impact the person's ability to access, engage with and benefit from an intervention. As such abilities in these domains need to be assessed over time, and the intervention offered needs to be adapted according to ability. There are machine learning based assessments already available, although these may need to be adapted for use in this project (21). Clarke et al. have suggested the use of machine learning and Natural Language Processing (NLP) to detect early Alzheimer's disease and mild cognitive impairment(22). However, we still need to identify the linguistic features that have a greater positive impact on the accuracy of the detection, and how the detection is affected by loneliness. There is no currently available evidence re which interventions for loneliness have the best efficacy at different levels of impairment.

3 Solutions proposed

An overview of the different stages of the proposed project is available in Appendix 1. The project has been divided into four chapters, which represent different research stages and funding streams. The project will be overseen by a steering group. The steering group will include key stakeholders including PwD, carers, psychiatrist, expect in machine learning, research lead and a facilitator.

Maximising the accessibility and efficacy across different levels of loneliness, cognitive impairment, and intersectionality

There is no evidence available about how people with dementia with different levels of loneliness, cognitive impairment and intersectionality experience loneliness. Furthermore, there is no evidence available about how these potentially divergent groups want an intervention to be tailored to their needs to maximise accessibility and efficacy.

We propose to utilise an Experience Based Co-Design (EBCD) methodology to address this problem. EBCD is one of multiple co-production techniques that have emerged separately but share at their core a concept of engaging service users/stakeholders/citizens in a creative process for service design or product development (23). EBCD has been used widely in health and social care to include patients and other stakeholders in health service design and production (24).

Co-design has been found to be beneficial when working with PwD; both for the project outcomes and the PwD who participate (25).

Concerns and considerations of co-design working with PwD

Potential challenges of co-design working with PwD have been raised and will require careful consideration and ethical review to ensure the project has appropriate safety and rigor. This includes ensuring inclusion of PwD who have different severities of cognitive impairment and who's symptoms limit verbal communication. Ensuring that the process is not distressing for PwD and does not lead to a significant increase in carer burden. Investigating reasons for 'drop-out' and ensuring that this is not due to detrimental effects of the process. Designing scaffolding for the process that overcomes challenges with continuity of information which is limited by memory impairment (25).

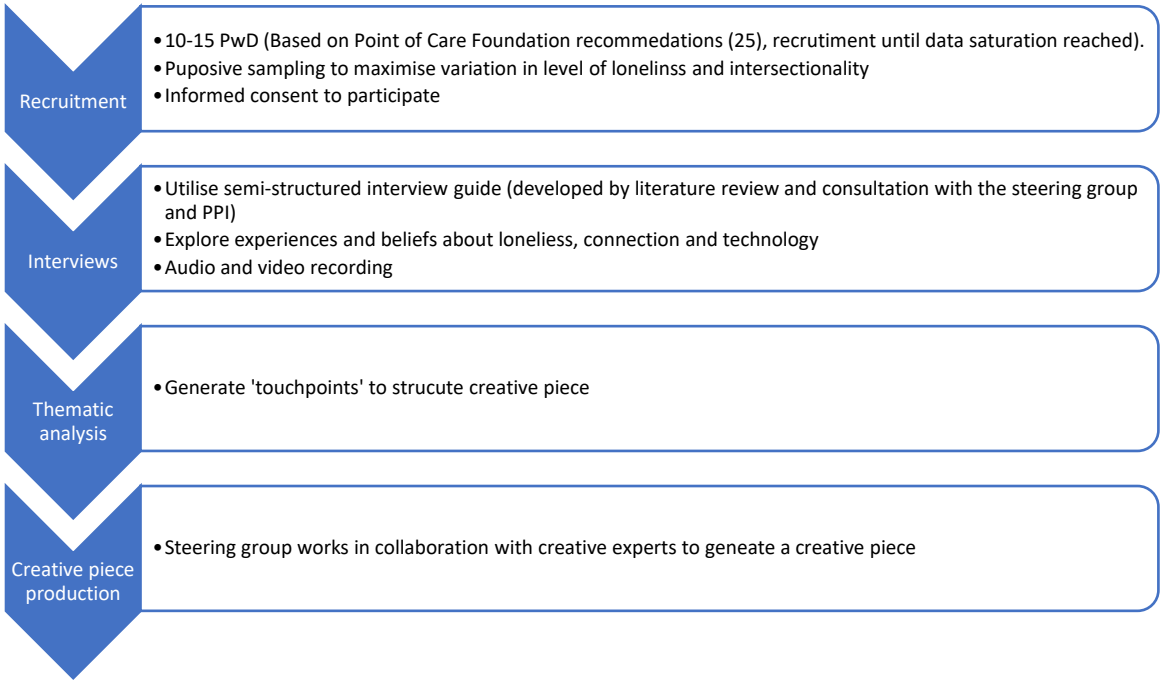
Another consideration is that co-design is often treated as PPI which does not involve external peer or ethical review. However, used in mental health with vulnerable people robust consideration consent, anonymity, confidentiality, burden of participation and potential risks is required and as such will be treated as research (26).

Proposed methodology for EBCD

This methodology is adapted from The Point of Care Foundation guide to EBCD, adaptions have been made to ensure ethical and methodological rigor (27). This process underpins Chapters one to three of the project.

Chapter one

Chapter one starts with formation of the steering group and for the purpose of EBCD ends with the creation of the creative piece.



Chapter one will generate understanding of PwD's experiences and beliefs about loneliness across intersectionality and loneliness severity. This addresses problems 1, 2a and 3 as described in Section 2.

Chapter two

Chapter two uses the creative piece to influence and form two activities. The first is to inform the creation of a semi-structured interview guide to generate interview data from PwD across severities of cognitive impairment. The second is to inform the creation of an observation guide and provide a framework for a creative community event that will allow stakeholders to experience and evaluate provocative prototypes and existing technological interfaces. The outputs from these two activities will be synthesised to generate the concept for the proposed technology to reduce loneliness in people with dementia.

Chapter two provides insight of loneliness, connection and technology across levels of cognitive impairment (Problem 2a and 4) and informs design to maximise accessibility and acceptability (Problem 1)

Chapter three

The concept generated in Chapter two will be utilised by a co-design group including PwD, carers, technology experts and other stakeholders to develop the technology. By using a co-design group that includes PwD across different levels of loneliness and dementia severity and representing intersectionality Problems 1 to 4 will be further addressed.

Assessing loneliness – machine learning solution

For the technology generated to adapt the intervention, based on loneliness level in a responsive way over time, it will need to assess the level of loneliness. This needs to be done based on the PwD's interaction with the technology through analysis of speech. In Chapter one interview transcripts will be generated from PwD across different levels of loneliness and intersectionality. This will generate textual data for analysis to create an initial loneliness classifier. Participants in Chapter one will have their level of loneliness assessed to provide an objective measure to inform the analysis.

The number of people experiencing loneliness is increasing, social isolation is a contributing factor to this (28). Hence, the use of artificial intelligence (AI) technology has been explored to measure loneliness. Notably, the use of AI in combination with NLP has been considered to quantify sentiment and features that indicate loneliness in transcribed speech text (29). However, this work has concentrated on older adults, and we aim to exploit the potential of this technology among a wider range of people.

Natural language processing (NLP)

Natural language processing (NLP) is a method of analysing natural speech for meaning and patterns to allow interpretation by a technology. In our project we intend to use this to assess if the PwD using the technology is lonely and if so the level of loneliness.

NLP is concerned with the ability to understand text and spoken words in much the same way human beings can. NLP combines computational linguistics with statistical and machine learning models. Together, these technologies enable computers to process human language in the form of text or voice data and to 'understand' its full meaning, complete with the speaker or writer's intent and sentiment. In the following subsections, we will describe the NLP tools and approaches which we intend to employ in our research.

Sentiment analysis

Sentiment analysis encompasses a series of methods and heuristics to detect and extract subjective information, such as opinion, emotion, and attitudes from language (30). The recent proliferation of research on sentiment analysis has encompassed applications on competitive intelligence (31), public health research (32), syndromic surveillance (33), and many others. Lately, it has been demonstrated that word use is a reliable indicator of a person's psychological state (34). Thus, sentiment analysis has been used to analyse people's evaluations and attitudes towards products, services, and topics, but most of this work has focused on assigning a positive or negative rating (polarity) to a piece of text. Loneliness is more complex than this and a more nuanced approach is needed. As such we will supplement analysis of sentiment (positive, negative, neutral) with a deeper analysis of categories including emotion (happiness, sadness, fear etc) and/or mood (depression, fatigue, etc).

Keywords and topic modelling

To identify the words and phrases that are the most likely to appear in the speech of a person experiencing loneliness, we propose to employ term frequency-inverse document frequency (TF-IDF) values. TF-IDF values can identify changes in word use frequency over time and highlight the most characteristic terms used by lonely people. Our previous work on unsupervised algorithms to automatically acquire the set of keywords that best characterise a person's speech suggests that the TextRank algorithm may be the best approach for us to carry out this task (35).

Along with the identification of keywords, we will make use of topic modelling to discover the themes that run through the speech or text produced by lonely PwD. Topic modelling is a technique that can be used to infer hidden topics in a collection of interviews or paragraphs written by someone. The two main outputs from generating a topic model are:

- A list of topics (that is, groups of keywords that frequently occur together within the speech of a lonely PwD) and
- Lists of the interviews or paragraphs that are strongly associated with each of the topics.

Profile of Mood States (POMS)

The Profile of Mood States (POMS) is a psychological test for assessing an individual's mood state, which was formulated by McNair et al (36). POMS measures an individual's mood (37); thus, it is of relevance for clinical and social psychology. POMS specifies 65 adjectives that are rated by the individual on a five-point scale. Each adjective contributes to one of seven categories: anger, confusion, depression, fatigue, friendliness, tension and vigour. For example, an individual who uses adjectives such as exhausted, worn out or weary to describe her own mood would contribute to classify her state within the fatigue category.

Most of the recent literature on emotion identification has adopted supervised machine learning approaches which identify specific sets of emotions. An example of this is Chaffar and Inkpen's research, which combined emotion-annotated news headlines, fairy tales, and blogs to create a suitable training set (38). Chaffar and Inkpen claim to have achieved a much better performance with a support vector machine (SVM) classifier than with any other alternative. Moreover, their SVM classifier generalises well on unseen examples. Therefore, we plan to follow the same approach in the first place. Initially, we can use a training set derived from Twitter, but we would like to create our own annotated dataset in later stages of the project. We elaborate on this below.

Measuring accuracy; estimating error

We will use regression and binary-classification models to estimate the accuracy of our methods to detect individuals with high loneliness scores. Regression model performance will be evaluated by using the mean absolute error (MAE), and root mean squared error (RMSE).

Training the classifier with more data – across loneliness, cognitive impairment, and intersectionality

Data is an integral part of all machine learning algorithms. Hence, in Chapter Two, data from interviews across the spectrum of cognitive impairment and intersectionality will be generated. To build truly a reliable model, we must provide data that is properly structured and labelled, and this is where the process of data annotation comes into play. We will annotate our data so that the machine learning algorithms can use it to learn how to perform given tasks. Annotating textual data largely encompasses adding relevant information, such as metadata, and assigning them to a certain class. Such data will be used to refine the loneliness classifier and introduce the variable of severity of cognitive impairment.

A method for analysing level of cognitive impairment by analysis of speech has already been produced (21), however this method asks a person to describe a picture not natural speech so will need to be adapted. The process of adaptation will follow the same method of measuring accuracy and estimating error as described above.

There is a risk that relying on speech alone will limit the effectiveness of the novel classifier to identify loneliness in those with severe cognitive impairment. All the interviews (Chapter one and two) will have been video-recorded to enable the potential for facial pattern recognition of loneliness if indicated. The rationale for this will also be informed by the creative community event where the use of provocative prototypes will explore people's perception and acceptance of this methodology.

The outcome of Chapter two will be a classifier for loneliness that is validated across different levels of cognitive impairment, loneliness and intersectionality.

Producing a technology for loneliness in people with dementia

The nature of this project is that the concept for technology is generated by a creative process and co-design. There are some aspects of the concept that are anticipated based on literature review and existing technology as listed below:

- Intervention that is adaptive over the dementia journey
- Providing connection
- Intuitive user experience
- Reducing loneliness
- Interaction with technology – e.g., chatGPT based

An illustrative example of how the technology might look is provided below. This is for illustration purposes only as the final concept will be produced by the EBCD process. For this example we have imagined a smartwatch based interface, the written text is a representation of verbal communication.

4 Future work

We have successfully defined that an intervention for PwD to reduce loneliness needs to be co-produced to maximise accessibility, acceptability, and benefit. There is clear evidence in the literature that this will need to encompass an interface that is accessible to PwD independently and that will adapt to the individual's interests, loneliness, and cognitive impairment over time.

The proposed project has been divided into four Chapters (Appendix 1). Each Chapter represents a distinct phase of the project with different proposed funding streams and measurable milestones.

Chapter One

The aim for this Chapter is to be funded by the n-code seed funding. This would allow an initial loneliness classifier to be developed alongside a creative piece as part of the EBCD methodology. Measurable milestones are the classifier and creative piece. Academic outputs will include publications in peer reviewed journals and conference presentations.

Once funding has been confirmed this Chapter will be completed in 12 months.

Chapter Two

A funding application to UK Research and Innovation (UKRI) / Arts and Humanities Research Council will be made to fund Chapters two and three of the project.

There are three measurable milestones for this Chapter. The first is the creative community event which forms the core of the EBCD process to develop the interface and intervention for loneliness in dementia. The second is the concept for the technology that will provide the parameters for the co-design group in Chapter three. The third is the refined loneliness classifier which can identify and quantify loneliness across intersectionality and severity of cognitive impairment.

Chapter three

Chapter three ends in the creation of the technology to reduce loneliness in PwD. It will be the result of a co-design process including PwD, carers and other stakeholders. The resultant technology will be produced at the end of the chapter and be ready for testing in clinical trials.

Chapter four

This Chapter will require a further funding application. We aim to provide evidence of efficacy for reducing loneliness in PwD via a large-scale trail with robust quantitative methodology.

5 Discussion and conclusions

The number of PwD is increasing and is projected to continue to increase over the coming years (1). PwD are at increased risk of experiencing loneliness, loneliness has significant detrimental impacts on physical and mental health and has been shown to increase all-cause mortality (2–4,12). Interventions that reduce loneliness are not only beneficial to the individual they can also reduce carer burden and are likely to be cost saving to health and social care (17).

The acknowledged diversity in the population living with dementia is increasing (39), intersectionality may influence individuals experience of loneliness in dementia and the benefit of interventions to reduce it. As such there is an existing and growing need to allow interventions to be tailored to an individual. This is further complicated in dementia as over time people experience a 'rolling back in time', connecting with the identity and interests of their younger self.

To provide this level of adaptable personalisation the technology itself needs to have the ability to recognise and classify change in loneliness, cognition, and interest. The first step to achieving this is to generate a loneliness classifier. We have demonstrated that although existing NLP methodologies have some promise they need adaptation and validation to achieve accurate real-time assessment of loneliness. This needs to be done across different levels of cognitive impairment and consider the potential influence of intersectionality.

Once we have created a validated NLP based assessment this will need to be integrated into a technology that delivers effective individualised interventions to reduce loneliness. An effective and evidence-based methodology to achieve this is Experience Based Co-Design which will bring together PwD, carers, technology designers and other stakeholders to create the technological intervention.

The resultant technology has the potential to impact the lives of hundreds of thousands of people. In the UK alone it is projected that by 2050, 1.6 million people will be living with dementia (1,40). Around 38% of PwD experience loneliness, even if only a third of PwD benefit from this intervention that would represent over 200,000 people in the UK alone.

There is limited research available into the economic impact of loneliness in PwD to inform a prediction of the potential cost benefit of this intervention. However, research in the elderly population suggests interventions that reduce loneliness are modestly costs saving (17). Given the large number of people that could benefit this could multiply to large cost savings overall.

Furthermore, the benefits to the individual people who are living with dementia are potentially huge.

> "The people are so friendly and helpful. It stopped me bottling everything up and going into a downwards spiral." (41)

This quote is from someone who attended a memory café, currently not everyone is able to access this benefit. Our technology will overcome these barriers and allow people with dementia to experience connection and reduced loneliness regardless of their ability to attend face-to-face meetings.

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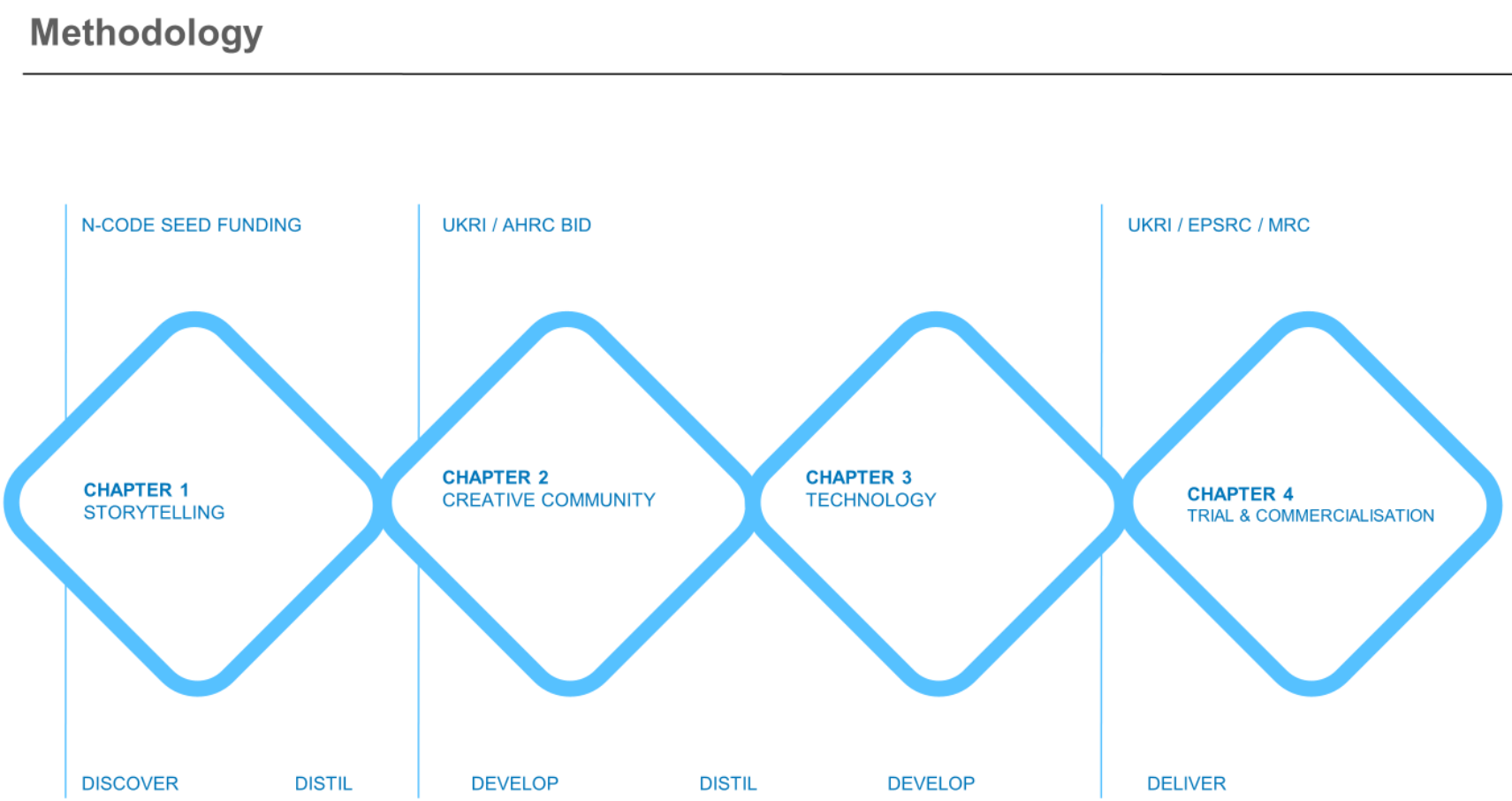
7 Appendices

Appendix 1: Project overview