

Health-based information for people with intellectual disabilities: an investigation into the linguistic properties of 'easy read' literature and its contribution to the construction of meaning.

The Easy Read Project.

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Abstract

Health information is often conveyed in printed or digital form. This can present challenges to people with intellectual disabilities, many of whom experience literacy difficulties and are therefore disadvantaged in reading and understanding such information. 'Easy read' versions of health-related documents purport to circumvent these difficulties, but there is little evidence to demonstrate their effectiveness in doing so. The aim of the current research was to address how effective adapted health-based 'easy read' literature was in contributing to the construction of meaning for people with intellectual disabilities. Four studies investigated different areas of 'easy read' information and its use. 1. A survey compared presentational features found in 'easy read' and 'non-easy read' literature published by the UK Department of Health and aligned these with advice given in published guidelines for 'easy read' material. 2. Critical differences between the linguistic features in these two groups of documents were analysed using specialised software. 3. A systematic qualitative linguistic analysis was undertaken to investigate the subtleties conveyed through the discourse of 'non-easy read' compared to 'easy read' texts. 4. Finally, a randomised experiment tested the effects of linguistic simplification and literacy mediation on the understanding of 'easy read' information with sixty participants with intellectual disabilities. When material was compared to its 'non-easy read' counterparts it showed that clear differences had been rendered by authors of the 'easy read' documentation. These differences were indicative of presentational changes and reduced linguistic complexity. They did not appear to translate into more effective understanding of content by people with intellectual disabilities, whether human mediation was present or not. Individual capacity for language, however, was shown to be integral to the construction of meaning from 'easy read material'. This has implications for both the production and the use of 'easy read' material in practice.

Table of Contents

Chapter 1.	Introduction	8
1.1.....	The Easy Read Project.....	8
1.2.....	The political and social landscape	9
1.3.....	Challenges to understanding.....	14
1.3.1	Literacy and communication.....	14
1.3.2	Health literacy.....	18
1.3.3	Risks to health.....	20
1.4.....	Responding to the challenges.....	23
1.4.1	Social movements and legal responses.....	23
1.4.2	Reasonable adjustments.....	26
1.4.3	The concept of accessible information	27
1.5.....	Developing ‘Easy Read’ information.....	29
1.5.1	‘Easy Read’ guidelines and co-production	29
1.5.2	Current trends in ‘Easy Read’ production.....	32
1.5.3	‘Easy Read’ websites.....	33
1.5.4	Document design and ‘Easy Read’	38
1.5.5	Measuring linguistic complexity.....	41
1.5.6	The contribution of ‘Easy Read’ documents.....	46
1.6.....	Models of reading.....	51
1.6.1	The construction-integration model	52
1.6.2	The ‘Simple View of Reading’	54
1.7.....	Intrinsic factors of influence on understanding.....	57
1.7.1	Reading links with language.....	57
1.7.2	Reading and intellectual disabilities.....	58
1.7.3	Cognition and reading	62
1.8.....	Extrinsic factors of influence on understanding	65
1.8.1	Reading instruction.....	66
1.8.2	Literacy mediation.....	68
1.8.3	Expanding knowledge and understanding.....	70
1.9.....	Summary	74
1.10.....	Research objectives	75
Chapter 2.	Study A: A Survey of ‘Easy Read’ and ‘Non-Easy Read’ DoH documents .	79
2.1.....	Background to The Survey	79
2.2.....	Study A: Aims and research questions.....	85
2.3.....	Survey method	85
2.4.....	Survey results	99
2.5.....	Survey discussion.....	105
2.5.1	Limitations of Study A: The Survey	110
2.5.2	Conclusions and implications of Study A: The Survey.....	111
2.5.3	From document features to linguistic content.....	112
Chapter 3.	Study B: Linguistic Analysis. Making health information ‘easier’ to understand: a comparison of the linguistic features of UK DoH ‘Easy Read’ documents and their ‘Non-Easy Read’ counterparts.	114

3.1	Background to Linguistic Analysis	114
3.2	Study B: Aims and research questions	120
3.3	Linguistic Analysis method	121
3.4	Linguistic Analysis results	128
3.5	Linguistic Analysis discussion	134
3.5.1	Limitations of Study B: Linguistic Analysis	140
3.5.2	Conclusions and Implications of Study B: Linguistic Analysis	141
3.5.3	From linguistic content to discourse	142
Chapter 4.	Study C. Discourse Features. ‘Easy Read’ – simplification or reduction? Critical differences in the discourse of UK DoH ‘Easy Read’ literature and their ‘Non-Easy Read’ equivalents.	144
4.1	Background to Discourse Features	144
4.2	Study C: Aims and research questions	149
4.3	Discourse Features method	150
4.4	Discourse Features results	158
4.5	Discourse Features discussion	165
4.5.1	Limitations of Study C: Discourse Features	169
4.5.2	Conclusions and implications of Study C: Discourse Features	169
4.5.3	From paper studies to a randomised experiment	170
Chapter 5.	Study D: The Easy Read Task. The effects of linguistic simplification and mediation on the comprehension of ‘Easy Read’ text by people with intellectual disabilities: a randomised experiment.	172
5.1	Background to The Easy Read Task	172
5.2	The Easy Read Task method	176
5.3	The Easy Read Task results	192
5.4	The Easy Read Task results summary	194
5.4.1	Limitations of Study D: The Easy Read Task	195
5.4.2	From participants to The Easy Read Project discussion	196
Chapter 6.	The Easy Read Project discussion	197
6.1	Relevance Theory model of communication	198
6.1.1	The cognitive environment	201
6.2	The Easy Read Task material	203
6.2.1	‘Easy Read’ information: explicit language	204
6.2.2	‘Easy Read’ information: implicit language	206
6.3	The Easy Read Task	208
6.3.1	Influence of the individual skill set on the comprehension of ER material	208
6.3.2	Linguistic influence on the comprehension of ER material	210
6.3.3	Influence of pictures on the comprehension of ER material	212
6.3.4	The influence of decoding support and mediation on the skill set in the comprehension of ER material	213
6.3.5	Linguistic and mediation influence on the comprehension of ER material	217
6.4	Critique of The Easy Read Project	220
6.5	Conclusions and implications	221

6.6.....	Future research	223
6.7.....	Realising the value of ‘Easy Read’?	226
Abbreviations		228
References		229
Appendices		254

List of tables

Table 2.1.1	Summary of guidelines	82
Table 2.3.1	Survey measures.....	90
Table.2.4.1	Language: means for readability and heading counts for ER and N-ER texts and associated comparisons using t-test analysis and Fisher’s exact test...100	
Table.2.4.2	Layout: use of columns, figures, images and white space in ER and N-ER texts and associated comparisons using chi-squared or Fisher’s exact test analysis 101	
Table.2.4.3	Images: source, type and colour in ER and N-ER texts and associated comparisons using chi-squared or Fisher’s exact test analysis	102
Table.2.4.4	Typography: font size, style and colour in ER and N-ER texts and associated comparisons using chi-squared or Fisher’s exact test analysis	103
Table.2.4.5	Production: document length and other support in ER and N-ER texts and associated comparisons using chi-squared or Fisher’s Exact Test analysis..104	
Table 3.3.1	Coh-Metrix measures	123
Table 3.4.1	Means for ER and N-ER Coh-Metrix main indices	130
Table 4.3.1	Document names and codes for discourse analysis	151
Table 5.2.1	The Easy Read Task questions	185
Table 5.2.2	Reciprocal reading definitions and steps	187
Table 5.2.3	Script to guide mediation with Text A.....	188
Table 5.3.1	Comparison of characteristics, baseline measures and The Easy Read Task scores across conditions	192

List of figures

Figure 1.5.1	Example of Widgeo symbols from Zed's Easter Visit	48
Figure 4.3.1	ER and N-ER text example annotated for referential function.....	153
Figure 4.3.2	ER and N-ER text example annotated for interpersonal function	154
Figure 4.3.3	ER and N-ER text example annotated for textual function.....	156
Figure 5.2.1	The Easy Read Task recruitment and allocation process.....	177
Figure 5.2.2	TERA measures for The Linguistically Simple Text.....	183
Figure 5.2.3	TERA measures for The Linguistically Complex Text.....	184
Figure 5.2.4	Procedure for The Easy Read Task.....	186
Figure 5.3.1	Interaction between factors: linguistically simple text and mediation	194
Figure 6.1.1	Schematic diagram illustrating key components of the cognitive environment	202
Figure 6.2.1	ER as a factor of influence within the cognitive environment.....	204
Figure 6.3.1	ER and the individual skill set as influencing factors within the cognitive environment	209
Figure 6.3.2	ER, mediation and skillset as influencing factors within the cognitive environment	213
Figure 6.3.3	Individual skill set as the critical factor in in the cognitive environment for constructing understanding.....	218

List of appendices

Appendix Chapter 2. i	The Survey DoH documents.....	254
Appendix Chapter 2. ii	The Survey matched headings	259
Appendix Chapter 2. iii	The Survey headings with no match	260
Appendix Chapter 4. i	Discourse Analysis Texts 1E and 1N	262
Appendix Chapter 4. ii	Discourse Analysis Texts 2E and 2N	268
Appendix Chapter 4. iii	Discourse Analysis Texts 3E and 3N	274
Appendix Chapter 4. iv	Discourse Analysis Texts 4E and 4N	280
Appendix Chapter 4. v	Discourse Analysis Texts 5E and 5N	286
Appendix Chapter 5. i	Ethical approval.....	292
Appendix Chapter 5. ii	Ethical considerations	296
Appendix Chapter 5. iii	Publicity leaflet.....	300
Appendix Chapter 5. iv	Participant information sheet 1	302
Appendix Chapter 5. v	Consent form.....	307
Appendix Chapter 5. vi	Participant recruitment profile	309
Appendix Chapter 5. vii	Definitions of reading comprehension levels.....	311
Appendix Chapter 5. viii	Reciprocal Reading definitions	312
Appendix Chapter 5. ix	Linguistically Simple Text A, questions and scoring guide	313
Appendix Chapter 5. x	Linguistically Complex Text B, questions and scoring guide	325
Appendix Chapter 5. xi	Record sheets	337
Appendix Chapter 5. xii	'Easy read' support sheets.....	343
Appendix Chapter 5. xiii	Mediation scripts.....	345

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Para Mónica del Carmen Urquizo Cordero

Chapter 1. Introduction

1.1 The Easy Read Project

The Easy Read Project was named by a group of eight people with intellectual disabilities (IDs) in Norfolk who used 'easy read' (ER) material. All of them described individual health-related experiences that involved being given ER paper information by healthcare workers or receiving it in the post. These experiences were recounted positively and also with reservations that stemmed from a number of factors including not being able to understand the information or not having help to understand it (Buell 2015). A series of four studies made up The Easy Read Project and aimed to investigate how effective adapted health-based literature was in contributing to the construction of meaning for people with IDs. For the purpose of this series of studies, IDs are defined as 'including the presence of a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development' (Department of Health (DoH), 2001: 14).

The first part of this introductory section outlines the current political and social landscape in which ER documentation is currently situated. It examines concepts of literacy, health and the way in which health information has been communicated. There then follows a section on the kinds of challenges to understanding health information that people with IDs have faced and the risks this has presented to them. How these challenges have been met through legislation and the development of ER material is then described. The next section provides a detailed overview of models of reading, how reading abilities have been linked with language skills and the implications of these theories and findings when related to people with IDs. Intrinsic and extrinsic factors that may affect the understanding of information by people with IDs were then identified and discussed. Using Relevance Theory as a framework, the way that knowledge and understanding might be developed then fore-grounds a description of the four studies

that have made up The Easy Read Project. These are: Study A: Survey of ‘Easy Read’ (ER) Documents, Study B: Linguistic Analysis of ER and Non-Easy Read (N-ER) Material¹, Study C: Discourse Analysis of ER and N-ER Documents and Study D: The Easy Read Task. The first three studies investigated various aspects of ER material and compared these to N-ER documents, while Study D: The Easy Read Task, took the form of a randomised experiment. Full titles and outlines of the four studies are given at the end of Chapter One in 1.10 Research Objectives (p. 75)

1.2 The political and social landscape

Written forms of communication are a critical feature of everyday life. They fulfil different purposes in society, where information supports consumption of services, goods and supplies, and communication underpins social connections and friendships. Information and communication technologies (ICTs) continue to develop at a remarkable pace. Social networking sites such as Twitter and Facebook promote wide social interaction, but are also common channels of communication within healthcare and education (Hunt et al., 2015). For people with IDs, information in paper or digital formats offers opportunities for engagement in a wide range of topics that may support their participation and decision-making (Moni et al., 2007; Weymeyer et al., 2008; Weymeyer, 2015). It also means that those who experience difficulties with reading and understanding the written word can be disadvantaged in terms of developing knowledge and achieving personal goals, particularly in relation to their own health (Nutbeam, 2009).

“Easy read” (ER) literature is the name in the UK given to material specifically prepared for people with IDs who might experience difficulty reading or understanding. As a format for simplifying information, it has evolved over the last twenty years in the UK and is now commonly used as an extrinsic tool to support the understanding of written information.

¹ N-ER versions in this study refer to those documents that have been created without the features that typify ‘easy read’ information. They usually contain more linguistically complex text, have fewer images (if any), use smaller font and leave less white space on the page.

ER is typified by the use of large font size, more spacing, the inclusion of coloured images and usually contains text that is linguistically simpler than its comparator (N-ER) version.

People with IDs have a thinner margin of health and are more vulnerable to health inequalities compared to the general population (Dejong et al., 2002). Lower life expectancy and higher mortality rates have been linked to underestimates of poor overall health and a lower uptake of health screening in the UK (Emerson and Baines, 2010). Furthermore, being afforded fewer opportunities to develop knowledge about health and having poor understanding of health-related information have been associated with poor health outcomes and care (Gal and Prigat, 2005). Emerson and Baines (2010) identified poor literacy as one contributing factor that can affect individual self-determination in relation to health.

Self-determination has been defined as the 'attitudes and abilities' (Weymeyer 1995:111) that are necessary for an individual to make independent decisions that influence their quality of life. Wehmeyer (1995, 2015) concluded that to act with complete personal agency means being fully able to make such decisions, to state preferences or to take the opportunities to do so. Many people with IDs have reduced agency over their own lives, and as a result, are not given autonomy to make their own decisions. Agency is fundamentally part and parcel of optimal human functioning, and is underpinned by much more than whether a person can read. Keefe and Copeland (2011) argued that processing and understanding written information through reading is one of the elements that contributes towards the fulfilment of human rights by increasing the possibility for self-determination. Indeed, UNESCO (2005) upholds literacy as a fundamental human right. The most recent global report on education (UNESCO 2005: 31) stated their aim for universally 'literate societies' which they have worked towards over the last decade through an international programme called 'Education for All'. Literacy is described as the means to achieving other human rights.

Those who can use literacy skills to defend their legal rights have a significant advantage over those who cannot. Indeed it is often the poorest, most socially excluded and least literate individuals whose rights are violated by those with more power. Their inability to read, write and calculate keeps them from knowing what they are entitled to and how to demand it. It limits their ability to participate politically in society. It denies them a voice. (UNESCO 2005: 31)

Moni et al. (2011) have suggested that the failure to link literacy with autonomy and personal agency could explain the apparently weak historical and current endeavours to encourage literacy skills amongst people with IDs. This remains despite findings such as those from van den Bos (2007) that demonstrated how improved literacy can lead to a better quality of life through informed decision making, problem solving, and communication.

Definitions of literacy have taken various forms over the last fifty years as Katims (2000) demonstrated in a review of literacy practices with IDs populations spanning two-hundred years. These have moved away from a narrow functional description that once focused on formal educational skills taught for reading. Throughout the seventies and eighties, Freire (Freire and Macedo 1987) attributed literacy skills with the potential not only to 'read the word' but to 'read the world' and described them as a set of functions that can either empower or disempower people (1987: 3). Over the past 30 years, The New Literacy Studies (NLS) have generated a model that views literacy practices as they occur within a social and cultural framework. Papen (2005:5) placed literacy within this model, where it is seen as a social practice 'situated in discourses, social relationships and institutional contexts'. Framing literacy as a social practice has been used by Keefe and Copeland (2011) to argue for increasing literacy opportunities for people with extensive support needs as part of their overall education and as an acknowledgement of this as a human right. Additionally, Morgan et al. (2011) from their literacy work with adults attending day centres, concluded that the recognition of literacy as socially and

contextually shaped provided a platform for raising the importance of understanding and conceptualising information over and above reading words on a page.

Sperber and Wilson (1986) have developed Relevance Theory as a framework that can be used to explore how cognition and communication interact in the ultimate pursuit of meaningful (or relevant) information. In Relevance Theory, both intrinsic and extrinsic factors within a communication context shape interpretations of the assumptions made by those involved in the interaction. The processing of these lead to an understanding of information that is unique to the individual and also unique to the communication event. If meaningful personal relevance is an outcome of this process, Wilson and Sperber (2012: 608) consider it to have yielded a 'positive cognitive effect'. It can be argued that every interaction about health that includes ER material with people with IDs creates a unique set of assumptions that are open to interpretation. It might also be proposed that the purpose of ER material is to reduce the cognitive load in order to create the necessary elements for achieving a positive cognitive effect in terms of processing and understanding information. Relevance Theory therefore offers a suitable central framework for considering the the influence of ER material on processes of cognition and communication in this study and has been woven through this thesis to underpin analysis and discussion.

Allowing for this wider social view of literacy where context is key the assumptions made in any given communication event will be shaped by a variety of intrinsic and extrinsic factors and these may influence a person's potential to read and understand information. A number of researchers (Chanel et al., 2013; Hulme et al., 2012; Levy, 2011; Nash and Heath, 2011; van Tilborg et al., 2014) have identified various intrinsic factors that affected how well information was understood. These included reading abilities, visual processing, language levels and cognitive skills. Morgan et al. (2011) established that personal experience, motivation and attention control also fed into the effective application of these skills. Findings from the studies cited here will be discussed in more detail in relation to reading abilities and intrinsic factors in Section 1.7.2 below (Reading and IDs

p.58). Extrinsic factors include the conduit for the information, in the form of a paper document, digital print or audio format. Within these, the choices made in layout, the nature of the information (narrative or informative), and the use of written and spoken language contribute to the construction of a message. Whether these extrinsic factors, (including ER material) have contributed to constructing meaningful understanding of information has not yet been clearly shown.

A number of studies have evidenced successful and creative engagement with abstract, sensitive and difficult concepts in an attempt to generate meaningful interactions with people who have IDs and who might experience difficulties in understanding. Board games were productive in developing concepts of human rights in relation to health (Montenegro and Greenhill, 2015), and small-scale workshops on general health (Feldman et al., 2015), inclusion and health care delivery (Naaldenburg et al., 2015), and medication knowledge (Strydom and Hall, 2001) all showed some level of increased understanding of the topic by participants. Those in Naaldenburg et al.'s (2015) conference workshops on health talked about the importance of 'know-how' and of learning new information. Focus groups, drama (Donaghey and Anderson, 2015) and storytelling (Cameron, 2015; Grove, 2014) have also been used to construct meaning from information. Collectively, these studies have demonstrated evidence of an awareness of the fundamental and critical necessity for constructing conceptual understanding with people in a way that is meaningful. They showed that building concepts that help people to make sense of the world is not necessarily associated with ER paper or web-based sources of information. It would seem that a gap has opened up between the design-production aspect of information and the activities often used in practice for constructing meaning. If bridged, this could help to redefine how ER material is viewed and how it could be more effectively used.

Nevertheless, Papen (2009) and Tuffrey-Wijne et al. (2014) concluded that paper information continued to be the most common tool used within health and social care. Papen (2009) studied the interactions between patients and their GPs through semi-

structured interviews with forty-five second language learners over a two-and-a-half-year period. Crucially, information that related to health remained largely paper mediated despite a growing concentration on the use of online information. While studies in The Easy Read Project did not specifically address the medium of the internet, essential issues identified in studies of websites related to language (Bunning et al., 2010), layout (Waight and Oldreive, 2015; Williams and Hennig, 2015) and understanding (Karreman et al., 2007) were similar to those identified in ER paper documents. Notwithstanding, Chinn (2014) observed that research into adapted information both on paper and online continued to be weighted towards design and production with less attention to the processes by which people build meaning from them.

It has been established in the above section that literacy is part of everyday life through channels online and on paper. Literacy skills appear to be closely associated with the ability to make personal decisions which is one form of expressing autonomy. However, engaging with written information to make decisions, particularly about health is not a straightforward proposition for people with IDs. The process of understanding information is likely to be affected by a number of intrinsic and extrinsic factors. The following section outlines some of the main challenges that people with IDs often need to overcome in order to understand paper-based ER information. These are situated within the emerging framework of 'health literacy'. Factors affecting the uptake and use of ER material are further explored and the shortcomings of failing to construct meaning from information are discussed.

1.3 Challenges to understanding

1.3.1 Literacy and communication

Having good reading ability is the first and most obvious pathway to understanding information in print. Good language and cognitive skills are fundamental to making

connections between reading words on a page, understanding them and linking them to everyday life experience, past and present. Receptive and expressive language abilities, and particularly vocabulary knowledge have been demonstrated to predict reading skills in studies of people without IDs (Protopapas et al., 2013; Nation and Snowling, 2004). Arguably, people with IDs, who experience spoken language and communication difficulties and who have a lower vocabulary range (Browder et al., 2013), are more likely to find that text presents some challenges to understanding.

Koritsas and Iacono (2011) undertook caregiver interviews in Australia (n=659) and identified communication difficulties as the most significant secondary condition causing limitations to the overall health of the adults with IDs they cared for. Reading was selected as the second most significant limitation to health. The prevalence of people with IDs in the UK who experience communication difficulties and the extent of those difficulties is under-researched (van der Gaag, 1998, Bunning and Buell, 2013, in Hilari and Botting, 2013). Available estimates range from 50% (Enderby and Davies, 1989) to 81% (Law and Lester, 1991) within the IDs population. Kerr et al. (1996) showed that as a group people with IDs are at increased risk of experiencing communication difficulties. However, with the exception of Enderby and Davies (1989) who formulated their estimate based on a literature review, each of the cited studies used a small participant sample in a single setting with a reliance on third party estimates. Many key support staff were required to make judgments based on their experience of the person they were interviewed about. However, a number of studies have demonstrated that family members, key workers and carers consistently under and over-estimated levels of communication (Banat et al., 2002; Bradshaw, 2001; Jingree et al., 2006, McConkey, 1999; Murphy, 2006; Purcell et al., 1999).

With regard to the levels of reading ability in adults with IDs within the UK, estimates vary. Similar to the data for communication difficulties, available evidence does not provide a representative picture. This is due in part to recruitment that draws participants from those who self-identify as readers, which thus skews the sample. The wide spectrum

of literacy ability as described by Morgan et al. (2011) in Australia potentially includes 'non-readers' with profound and multiple IDs (PMIDs) or complex communication needs in addition to those living independently who can recognise some functional words and fluent readers who can understand most or all of what they read. Patterns of the language and reading abilities of children with IDs might be relevant, although it is difficult to extrapolate this to the adult population. Verhoeven and Vermeer (2006) in the Netherlands compared reading measures from 10-12 year olds with IDs (n=378) to a similar profile of children without IDs (n=1071). Overall, the children with IDs demonstrated lower reading skills than the children without IDs. These results were linked to the lower language scores found for this group which in turn were related to lower social competence measures when compared to their typically developing peers.

Research into the adult population with eighteen young people with Down Syndrome (DS) in Australia provided an average estimated reading age of eight years and one month (Moni and Jobling, 2001). All of the participants in this study were pre-identified as having some reading skills, although only nine reached above floor level on reading assessment and IQ measures were not undertaken. Jones et al. (2006) estimated a similar reading age (between six years and nine and a half years) on the reading comprehension of twenty-four adult service users in the UK. Participants in their study were all within the ICD-10 mild - borderline range (i.e. an IQ of 50-79). In summary, people with IDs have demonstrated poorer reading skills than those without IDs. Reasons for this could vary, some of which merit discussion.

Engaging in print-related activities in childhood has been emphasised as an important element in developing proficient reading skills in adulthood (Snow et al., 1998). Furthermore, being exposed to an environment where print is readily available can increase reading readiness. Snow et al. (1998) observed that where children are encouraged to explore and engage with print they are more likely to be able to identify letters, thus increasing phonological awareness and syllable awareness, and establishing an idea of the various uses of print. It might be argued therefore, that being exposed to

joint reading experiences could influence reading development. However, Iacono (2004) suggested that many children with IDs lost out on this activity compared to children without IDs, or they often played a passive role within shared reading due to the difficulties imposed by the complexity of their communication needs (Light et al., 1994 in Iacono, 2004:100). This suggests that children with IDs could be missing out on crucial activities in early childhood that would lay the ground for future literacy interest and skill development.

Many adults with IDs have not had adequate opportunity to learn to read in formal education, possibly due to sporadic school attendance as a result of health issues or from being more often excluded from school than their peers without IDs (Emerson et al., 2010). It has been suggested that poorer reading abilities could also be due in part to a preferred focus on learning functional life-skills in education. In the past, this has not necessarily included a drive to prioritise literacy (Yoder, 2001). Indeed, Iacono (2004:179) researched literacy instruction for people with complex communication needs and discussed the way that 'communication and self-help' were often prioritised over literacy by families and teachers. She suggested that this impinged on the expectations for reading achievement in both formal education and at home. Literacy instruction based on limited educational policies was therefore restricted to the recognition of a few functional words within the person's immediate environment (Iacono et al., 2001). This pattern might be predicted to continue into adulthood where the opportunities to develop literacy skills may be even more reduced. Examples of providing opportunities for twenty-two young adults with DS to participate and read about popular culture was demonstrated through interviews from Moni and Jobling's (2008) 'Latch on' project in Australia. Few participants had previously had the opportunity to engage with popular culture, and were often reported to be protected from it. The level of motivation and interest in literacy and willingness to apply existing skills increased in the group as a result of being provided with the opportunity to engage with current culture through literacy activities.

It would seem, despite a paucity of reliable figures, that a considerable number of people with IDs in the UK may experience a range of difficulties with literacy and with communication reflecting the heterogeneity of this population. The lack of opportunities to engage with print in early years, along with limits in reading instruction have contributed to this overall profile. Although creating information that is relevant for the reader could increase motivation and help to reduce the challenges that poor literacy and language impose, the difficulties with understanding information remain. This is particularly important when information is about health. The following section explores health literacy and how the framework might be applied in relation to ER information and its target population.

1.3.2 Health literacy

Clearly, being able to read, understand and apply written information about one's own health continues to play a vital role in keeping and staying healthy. Erickson (2005:3) described the relationship between literacy and health as 'bidirectional' for people with IDs. Good health will optimise educational opportunities, while better literacy feeds into improved knowledge for managing health. As mentioned, studies have shown that health care processes continue to be textually mediated (Papen, 2009). Paper was the format of choice for health professionals in Papen's (2009) study where participant interactions with GPs most often involved information leaflets, consent forms, prescriptions, charts and wall posters. Research from the discipline of health literacy provides a framework that measures an individual's capacity to increase knowledge of his or her own health thereby reducing inequalities and optimising the resources available. Nutbeam's (2000) original measures of functional, communicative and critical health literacy suggested that a range of skills are necessary to become competent in health knowledge and understanding. He described health literacy as 'what it is that literacy (in health) allows us to do' (Nutbeam 2000:263). Activities included reading and reading comprehension skills under the category of functional health literacy, using more advanced communication, social, cognitive and literacy skills to converse about any health issues with professionals,

family and friends as part of communicative health literacy, and the ability to critically weigh up the information in order to make an informed decision or to take action under critical health literacy.

Chinn's (2016) conducted a systematic narrative review of available research into health literacy for people with IDs and found that *communicative* health literacy has received little attention over the last twenty years compared to that received by *functional* health literacy. This supported her previous argument (Chinn, 2014) that the main practical focus has continued to be on functional literacy (the ability to read text) for this group of people. She described how an emphasis on this aspect in favour of others narrowed the possibilities for capitalising on human interactions (communicative health literacy) that could lead to a more successful expansion of health capabilities and the positive application of health information (critical health literacy). In line with Chinn's (2014; 2016) work, Papen (2009:24) has challenged the health literacy model for its emphasis on 'deficit' (located in the person's abilities) and promoted an alternative concept of health literacy alongside literacy as a social practice, bound by its content and context. She incorporated key informants into the resource structure where an individual's collection of skills and knowledge interacts with their network of people to create the potential for better health literacy. Key informants were identified as friends, family or other significant supportive people within the person's environment with whom they could communicate about their health. Both Chinn (2016) and Papen (2009) also reflected on the hierarchical and disempowering social relationships inherent in interactions between many health professionals and their patients. This further underlines the need for reliable networks of support for people who might find communication difficult within the context of health.

The component of *critical* health literacy for people with IDs was specifically explored by Chinn (2014) and she acknowledged that difficulties often lay in the analytical understanding and application of information in relation to the wider social determinants of health. She disaggregated the different components (functional, communicative and

critical), and explained that a lack of functional ability to read a leaflet did not preclude the ability to understand or apply information. For example, someone who might not have the literacy skills to read about healthy eating and exercise could have the cognitive capacity to understand the concepts and consequences of changing dietary habits and being more active. Furthermore, Chinn (2014) argued that the components that constitute health literacy should not be seen as hierarchical, nor mutually exclusive. This is also consistent with Papen (2009) who demonstrated that health literacy could provide a useful dynamic framework for looking into the construction of meaning from health information when considered alongside the power of social networks as a primary mediating resource. Indeed, failure to acknowledge that people with IDs can experience difficulties in one or more of the functional, communicative and critical aspects of health literacy leaves them open to risk.

1.3.3 Risks to health

Despite the efforts made to overcome marginalisation and vulnerability, achieving good levels of healthcare for people with IDs does not appear to be straightforward. Emerson et al. (2011) estimated that there were over 1 million people with IDs in England who had a much lower life expectancy compared to the rest of the population. Less than fifty percent of those people identified with IDs in Emerson et al.'s (2011) study received a health check in 2010. Emerson and Baines (2010: 6) outlined five main areas of risk associated with inequalities in health for this group, including established 'social determinants' (poverty, poor housing conditions, unemployment, social disconnectedness, discrimination). Other risks were those posed by existing biological causes of IDs, communication difficulties and lower health literacy, personal health risks and behaviour, and lack of quality healthcare and access to it. Heslop and Glover (2015) have reported that avoidable deaths amongst people with IDs are twice the number of those in the general population. They attributed this difference to a lack of good healthcare as opposed to an absence of public health interventions.

MENCAP's report, *Death by Indifference* (2007) cited six cases in England where a failure to focus on maintaining channels of communication and checking understanding with patients who had IDs resulted in fatal consequences. Following the MENCAP (2007) report, the Joint Committee on Human Rights (DoH, 2009) emphasised the importance of addressing barriers to communication experienced by people with IDs particularly in relation to health (Recommendation 74). More recent research into hospital care (Tuffrey-Wijne et al., 2014) demonstrated that recognising the need for a different approach is only the first step. Staff were reportedly unable to decide on what was needed to support communication and understanding, and the needs of patients with mild or moderate IDs were often overlooked. This suggests that superficial communication within healthcare interactions was presumed to be adequate but that staff did not easily take account of patients' actual levels of understanding.

There are a myriad of consequences when health information is not understood. It appears that people with IDs are often left unaware of information about alternatives that would enable them to have basic control over health (for example, choosing an appointment), or they are not given the details of information that could reduce stress and anxiety. Arguably, failure to negotiate meaningful exchanges of information can lead to uninformed decisions and restricted choices about health care. For example, basic information communicated successfully about an appointment would mean that the patient would understand the purpose of the visit. Mcilpatrick et al. (2011) told of one participant who turned up to a breast clinic for a mammogram without knowing what she was there for. Collins et al. (2014) interviewed twenty-six women with IDs about breast cancer and their support needs. All were reported to have literacy difficulties, and one of the biggest issues identified was understanding and interpreting routine information. Collins et al. (2014) stated that despite some information being available in ER, support for understanding was needed for this to be effective. They reported that further explanations about the non-invasive nature of the breast clinic procedure could help to reduce stress and anxiety.

Failure to clarify that patients have understood the correct information can cause further misunderstanding and missed opportunities for making changes or learning new things. Murphy (2006) included six people with IDs in focus groups to explore health consultations and demonstrated the frustrations of GPs when unsuccessful in conversing with patients who had communication disabilities. For example, Law et al. (2005) cited the case of a patient with IDs whose use of the word 'ankle' to describe the location of his injury led to the injury in his shin being missed. Had the doctor asked him to *show* where it hurt, rather than *to tell* him where it hurt, the misunderstanding might have been avoided. Similarly, Law et al. (2005) described the experience of a man with autism who understood 'pop on the scales' (to be weighed), more clearly when his mother translated it into 'stand on the scales'. Participants (n=134) who attended in Crockett et al's. (2015) study showed that nearly one third of their fifty participants did not engage with a physiotherapy programme to prevent falls due to being unable to follow instructions, unexplained non-compliance and lack of carer support. Decisions related to pregnancy and early childcare was a further area where the lack of informed choices impacted infants and children of parents with IDs as demonstrated by Tarleton et al. (2006). In addition, Porter et al. (2012) have shown how ill-informed decisions about their children's health meant that responsible parents with IDs risked having them removed from their care.

It often goes unacknowledged that the construction of understanding within health interactions can imply costs. Both time and financial resources were reported to be at a premium, particularly in the current climate of health and social care. Campbell and Martin (2009) acknowledged that extra time and preparation was required when carrying out a review of the 'expert patient' role of people with IDs in five Health Boards in Scotland. These costs were often overlooked or assumed into current services. As Chinn (2014) explained, the implementation of lifestyle choices for health is the end point of a process that begins with understanding information. Unfortunately the consequences of cutting corners can lead to serious failures. It can be concluded that people with IDs are at a higher risk of experiencing complications with their health and that some of this risk

could be reduced through strengthening various components of health literacy, with better attention to how information about healthcare is communicated and understood.

The following section looks at a number of responses made to address the challenges presented to people with IDs in understanding information. Historical influences from human rights movements and drives for inclusion have helped to shape the development of an information industry in ER material over the last three decades. Its evolution is traced out of the movement of social role valorisation (SRV) (Wolfensburger 1972; 1983) and the social model of disability (Oliver, 1986). More recently, the response has taken the form of legal requirements for making reasonable adjustments to information. Material designated as ER is identified as one form of reasonable adjustment and these are described, along with an examination of the conceptualisation of 'access' commonly in use. The evidence base for the efficacy of ER material in contributing to the construction of meaning is then reviewed.

1.4 Responding to the challenges

1.4.1 Social movements and legal responses

Current moves to outsource health and social care services that are already stretched, the shrinking of benefit provision and patchy protection from the state (Butler, 2015; The Guardian) is fostering a requirement for users of health and social care services to be watchful. Certainly the ability to read and understand information and the achievement of effective health literacy (Chinn, 2014; Emerson and Baines, 2010) is key to being able to speak out and make decisions about health care. The wide range of ER literature available on the internet demonstrates some level of demand for being able to find, read and understand information relating to personal health ranging from wellbeing (e.g. diet and exercise) to survival (e.g. managing medication). The presence of such documents would not have existed in the 1970s (Walmsley, 2001).

From that time (1970s), a number of models have fundamentally influenced approaches to address the challenges that people with IDs face within society. These evolved out of a growing consideration of human rights and self-determination for people with IDs that began in the sixties (Owen et al., 2009). The ideology of 'normalisation', strongly associated with Nirje (1970) and Bank-Mikkelsen (1980), both in Sweden, initiated an international shift from institutionalisation to inclusion, independence and citizen's rights for people with IDs. Wolfensberger (1972; 1983) influenced by citizen's rights movements, restyled normalisation into SRV arguing that while equality and human rights were important, true integration could only take place through genuine social contact and interaction. These arguments challenged the status quo and contributed to a move for de-institutionalisation. In parallel, the emancipatory work of the Union of Physically Impaired Against Segregation (UPIAS, 1975) was established in 1983 by Oliver (1986) as a working theory. In response to the established impairment focus on disability, Shakespeare (2012) writes of the social model of disability movement that emerged out of UPIAS, and that has been politically, instrumentally and psychologically effective in generating a major shift in thinking to the present day. Rather than being situated within the person, the barriers to participation and full citizenship for people with disabilities are to be found within society. While the parameters of the social model and its evolution are still debated Walmsley (2001) commented that along with SRV, it has continued from its inception to shape support services and systems for people with IDs within the UK.

Although the real driving forces behind the movement towards decommissioning institutions are difficult to map out (see Emerson and Hatton, 1996), closures finally started in earnest in the UK during the 1980s. With the gradual disappearance of large institutions, society woke up to the responsibilities of past failures, but also to a future that called for supportive inclusion, equality of opportunity and the care and protection of vulnerable people living in community settings. This gave rise to various activities related to daily living, which reinforced the visibility of people with IDs in the community and instigated new local and national policy. Valuing People (2001) marked the first three-year government plan outlining a strategy to improve the lives of people with IDs in the UK. There followed a re-working of the policy in Valuing People Now (2009) and a

range of documents emerged including The Delivery Plans² (DoH 2010-2011; 39E/N), policy consultations on finance (Valuing People Now Consultation, DoH 2007; 40E/N) strategy papers on self-advocacy (Valuing People Now New Strategy, DoH 2010; 33E/N) and also on health (Valuing People Now: Summary Report, 2009 -10; 36E/N). The development of ER material was fuelled by what Walmsley (2010:24) described as ‘the growth of the user movement in learning disability’ that precipitated the formation of a number of committees and self-advocacy groups such as People First (Buchanan and Walmsley, 2006). ER information became recognised as one of the support mechanisms in helping people to ‘speak out’ (Walmsley, 2010: 25). It was therefore originally installed in an effort to allow people with IDs to understand what was being discussed in various meetings and interactions and to facilitate expression within an environment that was then relatively new and unfamiliar.

Underlying the political drive for achievable levels of citizenship and inclusion, there is an acknowledgement that realistic, practical measures should be put in place. Shakespeare (2012), proposed an interactional model of disability borne out of the original social model. This is one where factors intrinsic and extrinsic to a person shape the nature of their engagement with society. The model accepts the individual strengths and difficulties that contribute to defining personal participation, while still holding society to account. Debate around the nature of normalisation and inclusion within a disability rights’ framework has also continued. More recently Culham and Nind (2003) extended the argument, warning of the real-life dangers inherent in becoming *included* to the point of becoming invisible. Perhaps from a similar standpoint, Shakespeare (2012) considered ‘universal design’ to be neither viable nor practical. He argued that the responsibility for overcoming challenges lay within the personal will to make changes in society in response to individual influencing factors. Legislation spanning the last twenty years in the UK has underwritten this responsibility, and framed it within the term reasonable adjustments.

² Full document titles can be found in Appendix Chapter 2 Survey DoH Documents where E=ER and N=N-ER.

1.4.2 Reasonable adjustments

Within a legal context, the Disability Discrimination Act (1995) and now The Health and Social Care Act (2012) have been instrumental in driving the move within government bodies and health organisations to reasonably meet the requirements of people that experience a disability in society. The term ‘reasonable adjustments’ first officially appeared in The Disability Discrimination Act (1995) (Part III (19 c.)). Applying this to physical, environmental and attitudinal barriers became a legal requirement in the UK with the aim of increasing participation in society. In the nineties, aspects of government policy and legislation moved towards defining ‘accessible information’ within the concept of reasonable adjustment. The Equality Act (2010) reinforced this position, and recently, following a consultation on an Accessible Information Standard (NHS England, 2015), an amendment was made to the Health and Social Care Act (2012, Section 250) specifying the term reasonable adjustment in relation to communicating information. Although organisations and institutions have been legally obliged to implement reasonable adjustments since The Disability Discrimination Act (1995), anyone who has communication disabilities or experiences difficulties in understanding information now has a legal right to request adjustments. These include the presentation of information in different formats (ER, audio, Braille and DVD) as well as the support of sign interpreters, communication workers, or carers and family members who might help to facilitate understanding. Except for the possibility of individual legal claims, no apparent efforts have been made to enforce this process. It remains to be seen whether people with IDs will make legal claims when faced with the absence of reasonable adjustments, particularly if they already experience difficulties in communicating about health.

It can be concluded that meeting the information needs of people with IDs has been influenced by historic movements through SRV and The Social Model of Disability, and these have been backed up by legislation. What this means in practice with the new Accessible Information Standard (NHS England 2015) has yet to be realised. Turner and Robinson (2011) commented that making reasonable adjustments is often seen as part of

a wider, holistic approach for ensuring good healthcare for people with IDs and this has powered the drive towards the continued production of ER material. Financial and legal investments are likely to follow the agreed Accessible Information Standard (NHS England, 2015) and if these are to prove successful, a clearer conceptualisation of what is meant by 'access' in the context of information needs to be established. The following section explores the term 'access' with reference to the work of Seale and Nind (2010). Consideration is given to whether the Accessible Information Standard (NHS England, 2015) will offer people with IDs more than they already have.

1.4.3 The concept of accessible information

The Accessible Information Standard (NHS England, 2015) raises awareness of the relevance of printed information. It has triggered a range of commentaries in reviews on social media, for example, on Twitter and in blogs (Northfield, 2015). A national consultation in England and Wales brought together the perspectives of users, co-producers, health and social care professionals, volunteers and communication professionals through a number of focus groups, interviews and online questionnaires. The resulting document presented a broad consensus representing all stakeholders and participants. It outlined a number of minimum standards for information to be made 'accessible', including the development of ER material. Unfortunately, despite legal backing for such material, there is no clear evidence base to demonstrate what value it brings to the creation of fruitful understanding of health and social care issues for people with IDs.

It remains to be seen if the implementation guide and legislative weight behind The Accessible Information Standard (NHS England 2015) can effectively change the quality of 'access' to information such that it becomes worth something to those who 'access' it. Perhaps missing from the initial preparation for consultation was a debate over the term 'access'. As argued by Seale and Nind (2010), overuse of the term in relation to people

with IDs runs the danger of rendering it meaningless. They point out that words such as 'participation', 'inclusion' or 'valuing diversity' have similarly become easy to use despite representing highly complex concepts and proving difficult to put into practice (2010:12). However, unlike the three latter examples, they reason that 'access' has not enjoyed the same academic attention or debate that might have allowed it to evolve. Going some way to address this they have defined it as:

...more than a one-off event of getting over the threshold and more a process of rallying various support mechanisms in negotiating a myriad of obstacles to meaningfully participate and derive benefit from something. Thus access happens in the minutiae of interactions in which new words are explained, practices are modelled, social episodes are opened up, small problems solved. (2010:12)

In recognition of the conceptual complexity of 'access', the current study does not adopt it as a simple marker of 'reasonable adjustment' in relation to information. Instead, with reference to Seale and Nind's (2010) definition of 'access', it is considered as a multidimensional process of participation and involvement within the context of constructing meaningful understanding of written information. This neutral backdrop to The Easy Read Project serves to avoid any direct link to current government policy and legislation. Without a clear plan for implementation and what is meant by 'access' it remains to be seen how The Accessible Information Standard will bring about effective changes. ER material was demonstrated to be a central feature in the strategy for implementation. The area of most concern expressed by health and social care staff in recent implementation workshops once again focused on how to produce it (NHS England, 2016) rather than on how to construct meaningful information while using it.

Given these ongoing concerns, the following section looks at the development, use and production trends of ER documents. It also examines the popular use of automated

readability measures for estimating how easy a document will be to read, and provides evidence for other reliable alternatives.

1.5 Developing 'Easy Read' information

1.5.1 'Easy Read' guidelines and co-production

As identified, ER material continues to be one of the most common devices used currently to address reasonable adjustment, particularly in health and social care settings (Tuffrey-Wijne and Hollins, 2014). Developments in this area have been encouraged and supported by national grass roots organisations (e.g. People First), government policy, e.g. Valuing People (DoH, 2001) and service organisations in the health and social care sectors. Walmsley (2010:25) traced the journey of 'accessible information' from its roots in the self-advocacy movement in the late nineties onwards. To avoid tokenistic participation, it became necessary to develop a process whereby people could understand what was being said and communicate about it more effectively (Townsend, 1998; Walmsley, 2001; Ward, 1998). Thus the ER document format emerged out of a parallel re-surgence of co-production. The idea of co-production was central to the principle of maintaining an 'equal and reciprocal relationship between professionals, people using services, their families and their neighbours' (Boyle and Harris, 2009: 11). Co-production in its truest form, as argued by Boyle and Harris (2009), transferred the locus of agency away from professionals and back into the domain of the service user, thus creating a force for effective change. The co-production movement made a comeback in the nineties particularly within community initiatives in disability and health (Needham and Carr, 2009) and has continued to inform the production of ER documents. The need for a system to exchange meaningful information that was reciprocally developed and could empower people was identified and co-production became the gold-standard for ER material.

The Plain Facts Project, run by Townsley (1998) and Ward (1998) was established to encourage the wider dissemination of pertinent research findings to those whom the research was about. In addition, the Information for All Project (Rogers and Namaganda, 2005, Ward and Townsley, 2005) also inspired and promoted co-production as a positive step towards creating documents that were responsive to the needs and requirements of people with IDs. Thirty different UK ER information providers were interviewed. Close planning with the target audience and collaborative testing of final drafts were key to the consideration of successful design despite the considerable financial and resource costs incurred. Benefits gained by co-producers included learning new things, improved reading and computer skills, experience using cameras and audio equipment, and increased self-confidence. These projects were instrumental in raising public awareness of the need to provide ways for people with IDs to understand information in print. Many other organisations began to embed the creation of ER material within a co-production model (Change, Picture symbols) and continue to do so.

Documents designated as ER are primarily, although not exclusively, targeted towards adults with IDs. ER is the term that has been adopted by producers, users and policy makers to refer to this body of adapted material. Any individuals who experience difficulties in reading and understanding written text might also be expected to benefit from using it, for example, those with communication disabilities, such as aphasia as a result of stroke, those with progressive neurological conditions, people with mental health disabilities and those who have poor literacy skills, to name a few.

Many published guidelines are available with broad recommendations for creating ER documents. These include sets of guidelines from :

- government: Making written information easier, (DoH, 2010),
- national charities: Making myself clear (MENCAP, 2002), How to make information accessible (Change, 2009), Clear and easy handbook in Welsh and English (Learning Disability Wales, 2013),

- health and social care groups: SCIE Accessibility Guidelines (Social Care Institute for Excellence, 2005), Make it Easy (Irish Association of Speech and Language Therapists, 2011), Guidelines for making things easier to understand (NHS Scotland, 2007).

At a wider level: Information for All (Inclusion Europe, n.d.) and Guidelines for easy-to-read materials (International Federation of Library Associations and Institutions (IFLA), 2010) also contribute to recommendations. More recently, guidelines have been developed at a national level for specific groups e.g. Developing Easy Read Information for Prisoners with Learning Disabilities (National Offender Management Service, 2014). There are also personal representations of advice available online for example, The Easy Read Ladder (Inklecomms, 2014). This is not an exhaustive list of the available guidance on the internet about adapting information to make it 'easier', but those mentioned have a strong focus on people with IDs as the target audience. Specifically, suggestions include advice for modifying language: to make sentences shorter, choose familiar, high-frequency words (words used most frequently in English), and to avoid complex grammatical structures such as the passive tense or negatives. In relation to layout, usually more white space is advised in pages of text, and font should be size 14 or above, in Arial style or similar (avoiding sans serif fonts). Text is almost always accompanied by coloured images (pictures, symbols, photographs or a combination of these) and guidelines suggest that these can help text comprehension.

The Accessible Information Standard (NHS England, 2015) plans to make co-production a mandatory step in ER production for those working in health and social care from July 2016. Nevertheless, they have not provided empirical support for how a focus on co-production of the final product is central to building useful understanding of information. There has been little research to support the generalizable effectiveness of positive association and preference that the construction process relies on. It is likely that if a particular group designs and produces a document, it will have gone through several iterations to arrive at a version that meets with consensus. By default, as observed by Schriver (1989), this document will receive positive reinforcement and evaluation by those who produced it. However, there is no evidence of how power is distributed, how

design decisions are collectively made and who has the final say. Admittedly, group members might also have generated their own positive learning process through working on the document but this does not generalise into a document that will be universally easy, liked or understood. As Voorberg et al. (2015) have commented, there remains sparse evidence to show that co-production will effect beneficial outcomes for the understanding of information by the wider target audience. Despite this, sustained momentum for the creation of ER material can be demonstrated through the examples provided in the following sections on current trends in ER paper production and in adapted websites.

1.5.2 Current trends in 'Easy Read' production

Over the last 10 years, production of ER literature has increased. MENCAP now has an 'Accessible Communications' area on their website that offers support and training in developing ER information. Local councils, national government and health and social care trusts currently outsource policy and public health documents for modification to the many national independent and third sector organisations that charge for this service (e.g. Voiceability, Easy on the i, Inspired Services Publishing, Change, Inklecomms, Photosymbols). Such material is often generated and used by health and social care services and self-advocacy groups in organisational and daily pursuits such as minutes of meetings, reports, campaigns, health and safety information and guidance on access to services.

The internet also provides a forum for many ER downloadable resources. For example, Easyhealth (2010) produces a range of freely available health-related documents and United Response (2013) has aimed in the past to provide news and current affairs with Easy News. Requests for ER information relating to specific life events (such as moving house or undergoing a non-routine medical procedure) are frequently posted on email circulation lists sent to national networks (UK Health and Learning Disability Network).

Professionals continue to look at ways of adapting assessments into ER formats, for example the Adult Social Care Outcomes Toolkit (ASCOT) (Turnpenny et al., 2015). Research ethics committees require consent forms and information sheets designed as ER for any projects that involve people with IDs or anyone who might find it difficult to understand written information (IRAS, 2011). This includes people with English as a second language, adults with acquired communication disorders (as previously mentioned), people with specific reading or language disorders and still others who do not read proficiently due to limited educational opportunity or motivation. Subsequent research reports and abstracts are now expected in ER versions for relevant journals such as the British Journal of Learning Disabilities (BJLD) and some organisations routinely publish conference proceedings in ER parallel to those that are N-ER. This can be seen for example, in previous events run by the International Association for the Scientific Study of Developmental Disabilities (IASSIDD, 2014). Most importantly, many people with IDs now request ER information at events, meetings or seminars such as was noted at a recent conference (Inclusion International, 2015). With the rise of technological interactions, attention has also turned to website information specifically prepared for use by people with IDs.

1.5.3 'Easy Read' websites

Despite the pressure to be literate that stems from a growth of social networking sites, and the increase of text and internet communication, Walmsley (2013) suggested that this channel also extends opportunities for people with IDs to lead fulfilled and connected lives. In line with the development of social media and technology, research attention has shifted from a focus on examining the effectiveness of paper information to studies of ER in digital formats (Bunning et al., 2010; Karreman et al., 2007; Kennedy et al., 2011; Waight and Oldrieve 2015; Williams and Hennig, 2015). The way information has been adapted for people with IDs on the internet has been evaluated in three main ways: the types of web features applied, their impact on information retrieval and finally their impact on comprehension.

Across nineteen websites designated for people with IDs, Waight and Oldrieve (2015) found wide variability in features used such as font size and style, background colour, language used, navigation features, use of multimedia and other features related to locating or finding the websites. This corresponds with previous work by Bunning et al. (2010) who measured linguistic variability across fifteen People First UK websites as compared with the Citizens Advice Bureau website set up for the general public. They found that the linguistic features varied broadly across different websites. Readability measures, similar in formula to the Flesch Kincaid (Flesch 1948) measure such as the Gunning Fog Index (Gunning 1969) were used to estimate the number of years of formal education required for someone to be able to read the text. Scores ranged from around four years to twenty-three years of age. Only three of the websites analysed reached the accepted level for universal accessibility set by the Web Content Accessibility Guidelines; WCAG 2.0, (Cooper et al. 2008). Other linguistic measures (such as the use of high-frequency words) were also found to vary widely. Given that there is little evidence to demonstrate what optimal design looks like for ER websites and documents, variation here might be positively interpreted as a reflection of genuine attempts to meet the information requirements of a highly heterogeneous population.

Excluding comprehension as a factor, the influence of website features on information retrieval by participants with IDs provides some insight into the influence of choices in production. Williams and Hennig (2015) measured ninety-four participants' speed in retrieving key information with and without the presence of images, using different font sizes, with both horizontal and vertical menu orientation. They also assessed participant preferences through semi-structured interviews after the experimental stages were complete. Findings revealed inconsistencies between reader preference and reader performance. Experimentally, larger font was perceived to increase text length and was processed more slowly. However, although participants were able to scan the small font more quickly, when interviewed they expressed a preference for the larger font. Similarly, in interviews they expressed a liking for pictures, but these made no significant difference to retrieval speeds measured experimentally. In fact, when carrying out tasks, participants focused strongly on reading the text to the detriment of processing the pictures and there

was a tendency to stop scanning the webpage when the task became more intellectually demanding.

Furthermore, rather than processing the page globally in an effort to integrate written and pictorial information, participants in Williams and Hennig's (2015) study processed the web features serially. This led to them arriving at pictures in a left to right sequence, processing them one by one but not necessarily connecting them meaningfully with the text. How information was presented and visually processed by people with IDs in their study may have had an impact on the way participants understood the information it contained. The incongruity between participant preference and performance could be explained by participants' familiarity with the accepted format of ER or by their received knowledge of common guidelines.

'Understanding information' is a core requirement of the commonly used guidelines (Cooper et al. 2008) created by the World Wide Web Consortium (W3C) in their Web Accessibility Initiative (2014). Ironically, after running workshops with thirty-one web designers, Kennedy et al. (2011) reported that nearly half of them found the W3C Guidelines confusing, and too difficult to understand or to implement in practice. The focus in Kennedy et al.'s (2011) study was on 'access', which implied improving search and retrieval rather than tackling the understanding of information by participants. van der Geest and Velleman (2014: 332) however, made a clear distinction between processes for simplifying text to improve 'access' and measuring the understanding of information in their study. They identified and extended the notion of 'product-orientation' to 'process-orientation' in discursive work on the implementation of government e-documents. These had been modified in digital form for readers with poor literacy skills, specifically including people with IDs. Despite following common guidelines for creating ER material which involved beginning each sentence on a new line and using words that were rated as high frequency, both participants with and without IDs complained about the lack of text structure and many participants with IDs could not read the high frequency words on the adapted websites.

Whether reading and understanding adapted information on a computer screen differs from reading paper ER material was not addressed. Nonetheless, van der Geest and Velleman (2014) demonstrated that conventions for simplification of ER material such as starting a new line for every sentence disrupted the flow of ideas and distorted overall text coherence, making it more awkward to read. Nor could high-frequency words always be read or understood by their participants with IDs (although these were assumed to be 'easier'). Some participants could not construct any meaning from the ER webpage and answered the test questions from personal experience or 'world knowledge' (2014:331). It would seem that following commonly-used ER guidelines in Geest and Velleman's (2014) study resulted in confusing the reader through using 'high frequency' vocabulary that was not easy to understand and by creating un-natural patterns of cohesion. Vocabulary that is known to the reader and clear, informative use of cohesive devices in the text contribute to language that is explicit and that can be understood more easily (Sperber and Wilson 1986). Rather than creating a text that was explicit and from which relevance might be optimally constructed, ER conventions in this case presented obstacles.

In Karreman et al.'s (2007) study, twenty adult readers with IDs derived greater benefits from the application of W3C guidelines and ER principles to websites when compared to twenty people without IDs. They measured the effects of adapted websites on information retrieval *and* on comprehension. Both groups improved their scores when answering text-based literal questions, but only the group with IDs improved their scores using the adapted website on questions that required inference and reasoning. For the group without IDs, no difference was noted in their performance on inferential questions between adapted and non-adapted websites. Karreman et al. (2007) suggested that their adaptations seemed to facilitate better inferential understanding for poorer readers. Unexpectedly, they also found that participants with IDs requested assistance significantly more frequently when working with the adapted site rather than with the non-adapted site but no possible explanation for this was given. Indeed, they also performed better on inferential questions on the adapted sites compared to the literal

questions and this might have been influenced by the fact that they had asked for more help with the more difficult inferential task.

It would seem that many of the principles for simplifying websites have been borrowed from guidelines previously established for ER paper material (Karreman et al., 2007). Findings from research into ER design features in websites and their influence on information retrieval and comprehension could therefore be transferable to the production of ER paper documents. While the research reviewed above has identified interesting patterns, it continues to raise further questions. In particular, how participants managed questions that required inferential processing (Karreman et al., 2007) was clearly different to how they managed literal questions. Importantly, the Geest and Velleman (2014) identified an apparent interference in the linguistic cohesion of texts (the links and references made by language) caused by following guidance to use a new line for every new sentence. This raised a question about advice in published guidelines that could affect the natural flow of language as it is read. Manipulating a specific linguistic aspect of the text, (in this case, cohesion) unintentionally through guideline implementation was revealed to inhibit clearer understanding of the text. Perhaps it is not surprising that participants with IDs requested more help to use the adapted website than they did to use the non-adapted website. The behaviour could be explained by an increase in motivation when participants were presented with visual and textual material that they viewed as relevant to them. According to Vygotsky (1978) in his work on the development of learning, presenting a person with a task that is just within their developmental capability but that edges them into the next stage of development is the ideal and most effective learning point, known as the zone of proximal development. It could be that the material that was viewed as relevant to participants was also more likely to be within their zone of proximal development. However, what combination of factors and features achieved increased motivation or facilitated an appreciation of relevance remains unclear.

To summarise, the last ten years have witnessed a rise in the production and availability of ER literature and related activities that can in part be attributed to the stimulus of a well-established discourse linking the lives of people with IDs to the social model of disability (Shakespeare 2015). Requirements for reasonable adjustment have been further embedded by the Accessible Information Standard (NHS 2015) within the legal framework of the Health and Social Care Act (2012). Additionally, potential benefits may be brought about by ER material aside from the simplification of information. It appears to fulfil a positive awareness-raising function through its physical presence keeping the issue of 'access' for people with IDs at the forefront of events, publications and services. However, informal reports that reinforce these positive functions (Buell 2015) are not sufficient to underwrite the benefits of ER material in contributing to the understanding of information. Clear empirical evidence for this remains limited. (The aims of the current study have been developed out of this gap in the evidence base and are further expanded in the outline of research objectives on p. 75.)

Although to date there has been a dearth of direct research into the efficacy of ER design on paper, there are a variety of studies that have been carried out in related disciplines and findings might be applied. For example, research that addresses public health, safety science and warnings is closely allied to the concept of health literacy and might be applied to the creation of ER. Literature investigating linguistic simplification of educational texts and adapted written material formulated for second language learners also provides useful knowledge. Their exploration of comparable processes of language simplification can be used to examine studies of ER material.

1.5.4 Document design and 'Easy Read'

Rudd et al. (2003) examined public literature on health issues and concluded that design was rarely carried out in isolation and good design should be responsive to the needs, abilities and requirements of the target audience. In her formula for effective design of

health information, Wright (2003) combined readability (how easily the message can be understood), usability (how able people are to apply, refer to or act on the information), likeability (whether the public will be interested in 'reading' the information) and most crucially, the reader's interpretation of the text in their own social context at a given point in time. Interpretation can vary not only between different users, but also between different 'readings' by the same user or users. These concepts can readily be applied to the design of ER health-related literature for people with IDs.

Evidence for the influence of design details (use of colour, images, layout and typography) has been found in disciplines of advertising and information marketing to the general public, particularly that of health (Wright 1980, 1999a, 1999b, 2003) and safety science and warnings (Silver and Braun 1993, Keyes 1993, Laughery and Wolgater 2014). Keyes (1993) observed that colour in a document attracts the eye before anything else, whether it is text, or a border or a block of colour and items of a similar colour tend to be grouped together regardless of their meaning. Silver and Braun (1993) found that the colours used also impacted on interpretation for example, red, orange and yellow communicated 'alerts' more readily than other colours and led the eye before blue and green. They also identified that colour was perceptually affected by neighbouring colours and although strategic use of colour could extend the visual limit for overload, too much colour had the opposite effect. Indeed both Keyes (1993) and Laughery (2006) noted that the use of colour can create visual overload. There is a demonstrated propensity for the liberal use of colour in ER documents, although it is rarely mentioned in connection with how it might affect cognitive processing or reading. Whether the use of colour, which colours and how much colour helps or hinders visual processing and understanding by people with IDs has not yet been addressed.

With reference to images, Wright (1999) has shown that it is not always clear if an image is being used to explain the text or to reinforce it. Furthermore, it has been shown that the level of iconicity of a picture or symbol will impact on its interpretation. Iconicity relates to how closely the image resembles the real world item it represents (referent).

However, Laughery and Wogalter (2014) commented that any interpretation of an image is subject to the experience and knowledge of the interpreter. Loncke (2014) has drawn from experience in the field of Augmentative and Alternative Communication (AAC), where images and pictures are key to the process of receiving and expressing information. He maintained that the meaning of specific images often required clarification or needed to be learned in order to be of functional use in communication.

The effect of layout on the user's search and interpretation of information has also been examined within the design of public health documents. White space is the space left between type, between lines, around images and in margins. Passive white space, between lines and letters is needed for efficient processing, and the choice of line spacing can make a difference to how easy a text is to track for reading. According to reviews of related work by Wright (1980, 1999) the selective use of white space encouraged the user to locate and process information unambiguously. Passive white space often left the reader feeling as if the document was not quite finished and participants found these spaces distracting. White space used well (relative to images and text) is known as active white space and this was reported to allow for clearer contrasts that drew the eye to headings and images. Active white space can have the effect of slowing a reader, but has also been shown to increase comprehension of print by up to twenty percent in educational texts by Lin (2004, cited in Yusypchuk 2010). Keyes (1993) and Ling and Schaik (2007) have also demonstrated that text alignment affected speed of processing and comprehension. Left alignment was shown to be preferable to justified margins and Ling and Schaik (2007) also commented that the alignment of text, the use of lines of similar lengths, and the use of columns or other variations of text placement created visual frameworks that should be considered for their impact on visual processing in relation to what else is on the page. The use of bullet points further contributes to a visual framework. Wolgater and Shaver (2001) demonstrated that these increased the overall search time for finding information about medical symptoms by twenty participants (without IDs) but they did not have an effect on readers' recall of information. In relation to font, Silver and Braun found that larger sans serif fonts were more easily read than small fonts on bottles of detergent by forty-four undergraduates as well as twenty-two

elderly people although attention to the relative size of fonts used in headings and subheadings was shown to have a bigger influence on the perceptual prominence given to a heading than the size of the font itself.

To summarise, the combination of design choices made i.e. the amount of colour used, the areas of space given to one feature relative to another, the location of headings on a page and the typography used, interact to affect the level of effort expended by a reader and subsequently their willingness to read the text (Wright 1999). Despite various suggestions in common guidelines about how to apply these features in creating ER material, there is almost no research evidence to show which combination of these adaptations facilitate a better understanding of information for people with IDs by decreasing cognitive load and increasing the chance of positive cognitive gain (Wilson and Sperber, 2002). Nevertheless, a number of approaches have been developed to evaluate the complexity of written information in other disciplines.

1.5.5 Measuring linguistic complexity

Readability measures such as Flesch Kincaid (Flesch 1948), SMOG (McGlaughlin, 1969) and Gunning-Fog (Gunning 1969) are freely available and often used by professionals, educators and researchers both within and outside the field of IDs to check the equivalent reading age of particular texts (Benjamin, 2012; Estrada et al., 2000; Gal and Prigat, 2005; Hurtado et al., 2014; Iacono et al., 2004; Moni and Morgan, 2008; Poncelas and Murphy, 2006). To some extent they provide common currency in the preparation of texts for certain target groups, particularly for reading instruction as argued by Schutten and McFarland (2009). However, they all use surface level linguistic features that involve formulas for calculating relative numbers of words in sentences and syllables in words to create a readability score. It is worth remarking that as a one-dimensional measure, a 'good' readability score can still be gained when the text is written in nonsense!

The reliability and validity of traditional readability measures have long been debated. Benjamin, (2012) reviewed a range of such automated measures and argued that traditional readability formulas such as Flesch Kincaid (1947) are often too simplistic to reflect the influence of discourse structures and the variability of style and language in the readability of texts prepared for an adult readership. Researchers have responded to the instability of these measures by devising more sophisticated automated software to do the job. While several are available, Benjamin (2012) argued that Coh-Metrix (McNamara et al., 2014) provides a system that most closely reflects psycholinguistic models of language processing. It generates a range of systematic linguistic measures at multiple levels (word, phrase, sentence, paragraph, text) on large databases of text. The specific measures have been described in more detail in Chapter 3 (p. 122), with reference to its application in Study B: Linguistic Analysis. Coh-Metrix has been rigorously tested for reliability and validity, and has been experimentally compared against traditional readability formulas.

Crossley et al. (2011) revealed that the Coh-Metrix measures revealed from a linguistic analysis of texts were significantly more closely aligned to the levels of difficulty shown by second language learners than the outcomes given by traditional readability measures. Also, Sydes and Hartley (1997) reviewed and compared five different websites offering readability measures and found that Flesch-Kincaid scores on a single text gave variable results depending on the website used. They reported that such measures have also encouraged the shortening of words and sentences in an effort to reduce a high score, thus conversely *increasing* the functional difficulty of the overall text. For example, Graesser et al. (2011) showed that attempts to simplify by substituting pronouns 'it, this, he, she, we' for noun phrases or longer clauses increased ambiguity if the reader wrongly connected the pronoun with what it referred to (referent). While Benjamin (2012) acknowledged the value of readability measures overall, he concluded that uncertain ground called for a more linguistically robust approach that represented human processing more closely.

However, although computational analysis provided quick accurate linguistic output suitable for large amounts of text, researchers still acknowledged there were elements of language in text that could not be effectively evaluated in this way. Linderholm et al. (2000) used causal network theory to repair 'easy' and 'difficult' history texts by using a number of principles to create clearer causal links. For example, they arranged text content in temporal order and made implicit goals explicit through elaboration. They also repaired breaks in coherence. Specifically, coherence was affected by a lack of explanation, situations where multiple references were incorporated and when the causal relations were very distantly related within the text. The repaired texts were presented to thirty-nine undergraduates. Both the less and more proficient readers benefited and were able to make inferences from the repaired 'difficult' text, but no difference was revealed from the repaired 'easy' text. Specifically manipulating causal cohesion in this way had more impact for readers when the text was 'difficult'.

Wolman et al. (1997) also found that addressing the causal connections in stories and increasing causal structure so that stories had a clear narration of events and outcomes along a timeline, had a positive impact on recall and the retelling of narratives by 8 – 11 year old children with IDs (N=20) and without IDs (N=38) although the children with IDs recalled less information and retained it for less time. The questions that Wolman et al (1997) asked that incorporated reference to causal structure were answered more accurately by all participants than those without. This supports the idea that efficient understanding of written language is affected by linguistic constructs at a level beneath the surface where meaning is built through making connections with words and concepts. The more complex a text was, the more it required adaptation of causal links for improving understanding in the target audience. Interestingly, reading ability in the Wolman et al. (1997) study did not correlate with recall performance for any of the participants. This suggested that they were relying on their own knowledge and construction of events to recall the stories rather than solely on reading the words in the text. Being provided with explicit links in a narrative allowed the children to construct meaning more easily. In Relevance Theory terms, the explicit and coherent nature of the

information reduced cognitive load and increased the cognitive gain to be had through the pursuit of relevant meaning.

The manual manipulation of linguistics in texts without help from automated systems revealed some of the more problematic consequences of simplification. Allen (2009) analysed the use of relative clauses in eighty-one newspaper texts that had been adapted for second language learners at three different levels of difficulty to examine the effects of intuitive simplification on linguistic cohesion and overall coherence. He found that relative clauses were often removed (2009:593), for example '*In addition to the ethics reform, the Democrats have pledged to raise the federal minimum wage...*' was reduced to 'The Democrats have also promised to raise the federal minimum wage...' which reduced informational content and also altered the meaning of the text. However, , other texts were elaborated in the name of simplification through the addition of clauses and he argued that this increased linguistic redundancy and could place extra burden on the reader. Simplifying text meant that sentences were often split which also negatively affected the coherence of the text by disrupting the thematic progression although he acknowledged that it made the texts more 'readable'. He gave the following example of a full sentence: 'The following year, *when* Mr Chirac criticised the American preparations for war in Iraq, he was attacked by the media in the US and Britain' and compared it with the split sentence 'In 2003, Mr Chirac criticised the American preparations for war in Iraq. Television and radion stations in Britain and US attacked him for this'(2009: 594).By introducing a new theme (media) in the second simplified sentence, the author effectively disrupts the progression of the established theme which was about something that happened 'last year' to 'Mr Chirac', and overall cohesion is thus reduced. Allen (2009) concluded by stating that 'simplification of form often makes an utterance more difficult to comprehend' (2009:595) and identified the prominent role played in this process by the author.

Indeed, the author is largely responsible for the choice of linguistic features, in relation to the way that readers and events are represented, the position of the author in relation to

the reader, and the way that information logically progresses through a text. Issues of power distribution and equality are particularly liable to being overlooked through computational analysis. Qualitative research into the linguistic cohesion and coherence constructed throughout a text can demonstrate the position an author has taken in relation to their audience. This is shaped in part by the author's level of awareness and sensitivity to the readers' needs and requirements (McNamara, 2013). It could also be argued that the author's political, social and contextual interpretation of the text topic and the perceived needs of the target audience will inform the final text. Parallels can be drawn with findings from conversation analyses (CA) of interactions between people with IDs and a range of conversation partners (Williams, 2011). CA described by Ten Have (2007) is one of several methods of analysing spoken discourse. Williams drew attention to the power held by researchers depending on the analytical stance they took and how this may have affected interpretations of transcripts. With this caveat in place, Williams has demonstrated through CA how choice and control in private and public settings can be powerfully shaped by the kinds of conversations that occur in everyday life. She argued that these are strongly linked to the formation of personal identity. While the value of investigating conversations in this way should be acknowledged, using forms of discourse analysis from a functional linguistic basis reduces the bias of researcher interpretation, as described in Linderholm et al. (2010) and Allen (2009). These latter studies explored qualitative interactional and ideological aspects of documented language relating to power and identity that are not well addressed through automated linguistic analyses. A focus on text-based material that can be analysed descriptively through functional linguistics also removes many of the variables of interaction that are open to multiple interpretations through latent analysis such as CA that attempt to capture and explain specific communication behaviours.

This section has provided a brief overview of the complexities of the processes of language simplification and also the loopholes inherent in using automated systems of measurement for simplified text, both old (Flesch Kincaid, 1947) and new (Coh-Metrix, Graesser et al., 2011). While automated software can be used to analyse large volumes of text compared to the limited number that can be manually analysed, the benefits of the

latter included the ability to manipulate and monitor how isolated linguistic features affect meaning at a deeper level for experimental purposes. Applying traditional and new systems of linguistic analysis to the measurement of language in ER material has not been overtly stated in advice given through ER guidelines (DoH, 2010; Inclusion Europe, n.d; MENCAP, 2012) although they have recommended making sentences short and simple. Findings reviewed here suggest that designing a responsive ER document with attendant simplified and meaningful text is not straightforward. The next section appraises the available research into ER material, with a view to its design, production, purpose and use, and also its ultimate contribution to meaning and understanding.

1.5.6 The contribution of 'Easy Read' documents

Whether ER in its paper form successfully achieves a balance between design and production when tested for its contribution to the construction of meaning has not been fully addressed. Several criticisms have been levelled at ER material for this reason. The 'product' focus on design was observed again by Chinn (2014) in relation to ER documents in her discussion on ER and health literacy. She commented that concentration on production has eclipsed the purpose of the material itself. Furthermore, Walmsley (2013) has argued that simplifying text risks reducing information to a point where it becomes meaningless. She demonstrated this by comparing excerpts from a document about legal and civil rights with the same section taken from the ER version. There is little to support a full understanding of the complex concept of 'citizen' in the ER version. Indeed, Walmsley argued, 'making ideas about rights accessible to people with learning difficulties may require more words, not less, and be more than a mere document can achieve in isolation' (2013:18). However, a scoping exercise with eighteen participants within the NHS, comprising a mix of professionals and people with IDs concluded that greater emphasis continued to be placed on production of material with considerably less focus on its use. Both Walmsley (2013) and Mander (2013) have commented on the discrepancy between the current proliferation of ER material and the comparatively small number of people with IDs who know about it or use it. The reasons for this are unclear. It

might be explained in part by the presence of policy and legislative content that is not perceived to relate to everyday life and could be of little interest to the target population. Other factors could also contribute to low uptake, including failure to match the adapted versions to the reading and cognitive needs of this largely heterogeneous group.

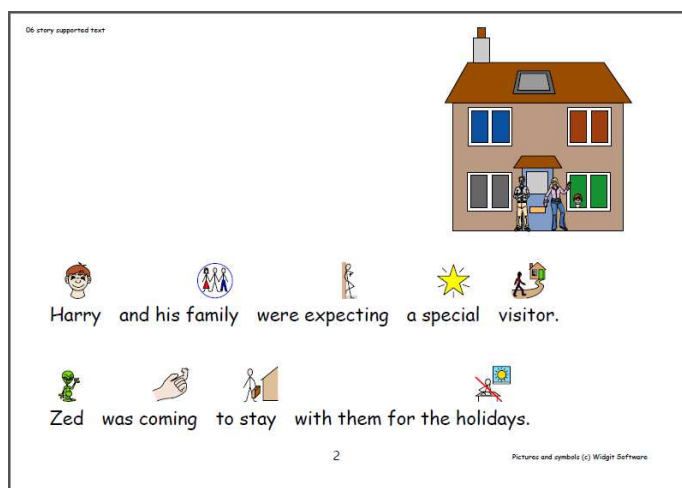
Participatory research has shown that people with IDs and information providers agree that ER literature engenders positive associations with inclusive practice and awareness-raising. Certain preferences and ideas have evolved about how the final product should look. Much of the evidence on production (Ward and Townsley, 2005) draws on experience of ER co-production and co-design. As mentioned (p. 47), outcomes from co-production processes related to The Plain Facts Project (Townsley, 1998) and the Information for All Project (Rogers and Namaganda, 2005; Ward and Townsley, 2005) were reported as positive. Although Walmsley (2010) described some of the difficulties involved, such as being able to faithfully represent information that was complex, the aim was to empower through communication. These were similar to outcomes identified by an advocacy group of seventeen to twenty-five year olds who wrote an ER book together (Wyre Forest Self Advocacy Group; Tarleton, 2005).

Nevertheless, most of the studies and examples still fall short of providing empirical support for the final product as a useful tool for building user understanding. There is little research to support the effectiveness of positive association and preferences in the construction of meaning from ER information.

Participant preference for how ER should look, particularly in relation to the use of pictures is at odds with the evidence for their contribution to improved understanding. Poncelas and Murphy (2006) gave ER versions of political manifestos with and without Widgit³ symbols (placed directly above each relevant word) to thirty-four adults with IDs. An example of Widgit³ symbols is given below in Figure 1.5.1.

³ Widgit³ is the company that designs symbols for support to written words (<https://www.widgit.com/>)

Figure 1.5.1 Example of Widgeit© symbols from Zed’s Easter Visit



Participants’ comprehension of the information was measured by a scoring system for partial or full understanding based on responses to set questions. Findings demonstrated that the symbols used made no significant difference to the participants’ comprehension of the text.

In contrast, Jones et al. (2007), found that Widgeit© symbols could increase the reading comprehension of some adults with borderline IDs when given passages from the Neale Analysis of Reading. Nineteen adults responded to comprehension questions after reading passages with symbols. Positive outcomes could be explained by the high number of participants with previous experience of using symbols (n=15). In addition, authors commented that symbols were attached to highly concrete words and were therefore possibly easier to interpret than if they had been allocated to more abstract words. Using a different source of images, Hurtado et al. (2014) presented simplified texts accompanied with pictures and also a version where text was removed leaving pictures only, to forty-four adults with IDs. A series of questionnaires were prepared in order to measure comprehension. Questions were asked at set points during the procedure while the texts were being read out to participants. No significant difference was subsequently found attributable to the use of pictures.

Away from a focus on deep level comprehension, Williams and Hennig (2015) aimed to test whether pictures in ER websites improved surface level information retrieval among one hundred and four participants with IDs. In fact, participants were observed to concentrate almost exclusively on decoding and understanding the text and did not pay attention to the pictures. As a result, their presence did not significantly affect participants' ability to retrieve information, despite their expressed preference for the inclusion of pictures alongside the text. Similarly, focus groups and interviews with participants with complex communication needs in Australia resulted in contradictory feedback. Participants wanted pictures, but only those that were relevant to them personally and they acknowledged that symbols were most useful when people were first taught their meaning (Owens, 2006). Overall, it might be concluded that the tenuous usefulness of pictures and images in ER material remains unclear in terms of their role in conveying meaning when provided alongside text.

Focusing on the text itself, minimal research was found that investigated the influence of linguistic conventions on reading comprehension of ER material. The two most relevant studies were carried out in Spain. Although ER guidelines have suggested that 'repetition is better than variety' (DoH, 2010:28), Fajardo et al.'s (2014) study of the repetition of terms found otherwise. They gave sixteen participants a series of ER news texts over sixteen weeks and asked literal and inferential questions to test comprehension. They found that the number of co-references in texts impacted significantly on the comprehension of ER literature by people with IDs. Contrary to expectation, participants performed worse when a higher number of co-referents was used in the texts. (Co-referents are words that refer back to previous information given in the text. They may be the same word repeated or they may refer back through the use or repetition of pronouns e.g. 'he, she, it, they, that').

Less surprisingly, the more sentences that were used in a text (possibly as a result of shortening sentences), the less able participants were to answer inferential questions about the content, demonstrating that a high memory load during a reading task

probably led to lower text comprehension. Participants were also de-motivated by texts that they perceived to be 'long'. In a previous study, Fajardo et al. (2013) looked at the impact of using high frequency (familiar) words and different types of connectives (words that join clauses: e.g. and, but, because) on comprehension in an online computer task. Sixteen adults with IDs were compared on their performance with two control groups without IDs (matched for chronological age and reading age). They found that neither the use of high frequency words, nor the use of more familiar connectives made a significant difference in facilitating textual understanding for the adults with IDs. This was explained in part by the fact that high frequency words are often more ambiguous than low frequency words which afford more specificity. Furthermore, as previously mentioned (van der Geest and Velleman, 2014) high frequency words were not always able to be read and understood by participants with unique literacy profiles particularly if they were situated in an unfamiliar linguistic context. This suggests that the construction of language for ER information is complex and it therefore deserves a robust approach that takes linguistic mechanisms and language meaning into account.

Despite a number of studies reviewed in this section that have contributed evidence for effective document design and production for the general public (Keyes, 1993; Laughler and Wolgater, 2014; Silver and Braun, 1993; Wright, 1999; 2003), and a large body of work that has captured the influence of certain linguistic modifications on reading comprehension in educational texts (Crossley et al., 2007; Crossley et al., 2008; Crossley et al., 2014; McNamara et al., 2010), there is still a lack of empirical evidence showing what combination of design features or linguistic modifications might lead to ER material that will improve the understanding of information. Participatory research has dominated the literature in the study of ER document production and use, (Owens, 2006; Rogers and Namaganda, 2005; Ward and Townsley, 2005; Tarleton, 2005; Walmsley, 2010) and these have provided a critical voice in terms of individual and group preferences and understandings. This raises important questions about the tension between participant preference regarding printed matter and reading/comprehension performance on the information presented. It follows that current ideologies in the production of ER literature expounded by common guidelines (DoH, 2010; Inclusion Europe, n.d; MENCAP, 2002)

warrant closer inspection. A review of research literature has demonstrated a strong commitment from stakeholders to the continued production of ER material, while a paucity of evidence exists that supports its usefulness in terms of helping to construct meaningful information.

In an effort to address this lack, a closer examination of how ER information is processed and understood will frame and substantiate the four subsequent studies presented within The Easy Read Project for this thesis. The following section takes the form of a detailed theoretical exploration of the possible intrinsic and extrinsic factors that may influence the construction of meaning. It starts with an overview of different models of reading and text comprehension. A detailed examination of these theories and how they represent the processes involved in reading will be provided to identify factors that influence the understanding of written information for people with IDs. Intrinsic factors will be considered, with a section specifically focusing on research into the reading abilities of the IDs population. Strengths and weaknesses of these abilities pertaining to the different models of reading will be discussed. The impact of other intrinsic factors such as motivation and cognition are also considered. Extrinsic factors are then explored drawing on research about ER literature itself, the involvement of human literacy mediation and where this fits into the wider concept of health literacy.

1.6 Models of reading

Reading has been variously defined as a multi-level, complex process. A large amount of research has focused on developing working models and frameworks (McNamara and Magliano 2009; Stuart et al., 2008; Roth et al., 2002) that can be applied to the preparation of reader-appropriate text and used to understand where breakdowns in reading might occur. Among these, are text comprehension models that have arisen out of connectionist theories such as the construction- integration model (CI) based on work by Kintsch (1988) and the Simple View of Reading (Gough and Tunmer 1986) which has been widely applied in educational contexts in the UK (Stuart et al., 2008). These two

models are examined in turn and provide the theoretical basis for the present series of studies.

1.6.1 The construction-integration model

The CI model provides a structure for considering the nature of text comprehension. The model focuses on how language is used to build cohesion (the way language creates links and references) in text and coherence (the meaningful integration of the overall message) from text. As part of the school of connectionist approaches, it differs to previous models in several ways, best outlined through its eight assumptions (McNamara and Magliano 2009). 1. Rather than a description of discrete events mainly related to memory, reading is the activation of parallel and simultaneous processes for understanding text. 2. The spread of this activation crucially creates links that are then made with other text based concepts. 3. The parallel and simultaneous processes that take place are largely automatic and function at a subconscious level. 4. Readers will read a text in a particular way depending on the goal they have established for reading it. This means that the reader is focused (consciously or subconsciously) on the discourse of the content and has the power to control his/her own attentional 'resources' (2008:305). 5. The strength of concept activation depends on its relation to other concepts that surround it within the text and the number and strength of those concepts in turn. Arguably, the stronger the relationships and more numerous the related concepts are, the stronger activation will be. These concepts will then become more memorable to the reader. 6. Mapping between concepts from the text takes place. 7. When mapping fails (due to a breakdown in text cohesion for example), the reader then generates inferences. (Inferential reasoning fills the gaps in textual information for the reader. Efficient inferencing depends on the ability to draw on information not explicitly represented in the text and to use this to build a coherent understanding of the text discourse.) 8. Readers can only process between two and four units of information (propositions) at any one time.

The value of a CI model is two-fold. It encourages a strong focus on how language is used in text for the understanding of core concepts and it reflects a realistic picture of the complexity of the processes involved. CI offers a model of how human beings construct meaning out of written information that can be usefully applied to an investigation of how ER material is constructed and how this influences the way it is understood. This makes it a suitable framework for beginning to look at the deeper structures that function within ER material. Research evidence into how much information is understood by people with IDs (Fajardo et al., 2013; Fajardo et al., 2014; Hurtado et al., 2014; Poncelas and Murphy 2006) revealed that superficial changes to layout (e.g. picture use) or language (shorter words and sentences) did not consistently produce the intended benefits.

Connectionist theories engage with higher level processing of meaning rather than lower level processes such as the decoding of letters and words and the ability to recognise grammatical constructions (syntax). As mentioned, Karreman et al. (2007), and Fajardo et al. (2014) assessed comprehension from online and paper ER versions respectively, and found that inferential questions caused more difficulty to participants with IDs than literal questions. Furthermore, the outcomes from Fajardo's (2014) study showed that repeated referents (which should increase cohesion) did not, in direct contrast to McNamara et al. (2010) and Linderholm et al. (2000), where such conventions increased the comprehension of text with non-IDs participants. This suggests that people with IDs may respond to textual cohesion in a different way, or it could be that producers are using a style of simplification in ER that is negatively affecting its coherence.

Notwithstanding, for many people with IDs, a barrier also exists at the surface level which involves the mechanical decoding of letters and words. Experiencing difficulties in decoding or recognising that a string of letters comprises a word (or even a non-word), will inevitably lead to difficulties with understanding text at a conceptual level. The CI model assumes an ability to decode, whereas The Simple View of Reading incorporates both decoding and semantic understanding as its two main strands.

1.6.2 The 'Simple View of Reading'

It has long been established amongst academics both in the fields of education (Torgesen et al., 1997) and cognitive neuropsychology of language (Coltheart and Leahy, 1992; Coltheart et al., 1987) that the development of reading depends on two fundamental and interacting processes: phonological and semantic. The typical adult reader has developed a sophisticated set of skills to access and understand text, and this usually takes place in childhood. Firstly, the reader must be able to recognise the particular text (for example, the Roman alphabet, Cyrillic script, Chinese characters) as units representing words. In English, this involves recognising letters and being able to decode them into words, otherwise known as phonological decoding. Secondly, once a word has been decoded from the page, it will trigger linguistic knowledge that is stored in the memory allowing the reader to make sense of what has been read. This includes grammatical knowledge (syntax) and a store of the meanings of words (semantics). Finally, the reader draws on real world knowledge and memory of previous personal experience to interpret the text.

Debate continues about the finer points of these processes and which plays the most dominant part in reading success. A longitudinal study by Roth et al (2002) measured oral language and reading skills in preschool children (without IDs) over a three-year period and found that semantic skills with print awareness rather than phonological abilities predicted early reading comprehension. Phonological processes in Roth et al. (2002) predicted ability largely at the level of word reading. They conceded that phonological and semantic processes were both necessary for successful reading but inferred that young children's ability to manage the meaning of words was one of the most significant predictors of their ability to read single words. In contrast, Nation and Cocksey (2009) tested twenty-seven seven-year-olds in UK primary schools and found no evidence to show that a deep semantic knowledge of words had much influence on reading success at this age. Rather, the initial ability to recognise an item as a word using phonological skills was found to be more critical.

The Simple View of Reading (Gough and Tunmer, 1986; Hoover and Gough, 1990) has frequently been applied in education practice and research. A study of thirteen children and young adults with Down Syndrome (DS; Nash and Heath, 2011) found that they had weaker reading comprehension skills than a control group without IDs and this was strongly correlated to their language skills. The participants with DS also had surprisingly more difficulty with the inferential comprehension questions than their reading scores would otherwise have suggested. So although they had good sight recognition for words (decoding skills), they did not perform as well on tasks that required sophisticated semantic processing and were shown to have similar profiles to 'weak comprehenders' without IDs. Henderson et al. (2013) researched how poor literacy comprehenders used the semantic domain to access word meaning. They tested seventeen 'poor comprehenders' alongside two control groups. Both the control groups were faster at selecting the dominant homonym from two pictures for example, choosing between 'bank' with 'money' (dominant) or with 'river' (subordinant). They were also better at inhibiting the wrong subordinate homonyms when completing sentences. The ability to access subordinate meanings through semantic processing was weaker amongst children who had weaker reading profiles which suggested that people who experience difficulties with reading will also find ambiguities in text problematic.

Concerns that The Simple View artificially isolates decoding and semantic processes have been expressed. Recent work by Protopapas et al. (2013) and others (Ouellette and Beers, 2010) has argued for a more inter-relational model. Protopapas et al. (2013) in Greece studied data from a substantial sample (n=436) of typically developing children (aged three to six) gathered over one year and showed that a large proportion of the variation attributed to reading and oral language measures could be assumed by vocabulary (semantic processing). They distinguished between the depth of vocabulary knowledge (the extent of the semantic representation of words) and the breadth of vocabulary (the number of known words). This built on similar research by Ouellette (2006) and Ouellette and Beers (2010) whose findings supported the contribution of both forms of vocabulary knowledge to reading comprehension in a highly complex interplay with phonological decoding, word recognition and listening skills. This research emphasised that the activity

of inter-relations within the lexical domain were what primarily contributed to reading comprehension rather than their function as a set of discrete components. Still, in spite of the specific nature of these findings, Protopapas et al. (2013: 197) acknowledged that a further proportion of the variation attributed to reading remained unaccounted for. They concluded that attempts at 'separating out isolated processes for reading 'may be futile' in clarifying what is essentially a multifarious system of processes.

Stuart et al. (2008) accepted that The Simple View of Reading is limited to a consideration of cognitive (word recognition /phonological) and linguistic (language comprehension /semantic, syntactic, contextual) processes. They emphasised however, that this did not detract from the complexity of the various dimensions involved. Positively, Stuart et al (2008) argued that the Simple View does not stipulate many inclusion terms, and therefore does not exclude the influence of socio-cultural factors, the stage or order that skills are acquired or the possibility of the on-going development of language comprehension throughout the lifespan. The flexibility built into The Simple View makes it a suitable framework for exploring reading and reading comprehension within heterogeneous populations and it allows for a social practice view of literacy as espoused by Papen (2009) and Morgan et al. (2008). Indeed, Sabatini et al. (2010) supported The Simple View against criticisms that the 'simple' nature of the model overlooked vocabulary or fluency factors. They demonstrated that reading comprehension amongst four hundred and seventy-six adult learners with low literacy measures was best accounted for by word recognition and oral language comprehension alone. They argued that expanding the model to include a distinct strand for vocabulary aside from non-lexical language processing and another for fluency of reading, would not functionally add to it.

The current study series has therefore adopted the CI model of text comprehension alongside The Simple View of Reading as a theoretical basis for investigating the production and use of ER material. The Simple View of Reading incorporates decoding skills, language capacity and semantic knowledge and provides a model that includes the

mechanical processes of reading, while the CI model provides a framework for investigation into the processes of meaning construction. Specifically, through the CI model, understanding information rests on an individual's contextual and background knowledge (the situation model). Together these theories provide a structured backdrop for the examination of reading for meaning with a heterogeneous target audience and are compatible with the central ideas of Relevance Theory (Wilson and Sperber 2002) which proposes that reducing cognitive load (in this case through making written material 'easier' to understand), is more likely to result in positive cognitive gain and increase the chance of constructing relevant information. The intrinsic processes known to be involved in reading and how these influence the understanding of written information are addressed in the following section.

1.7 Intrinsic factors of influence on understanding

1.7.1 Reading links with language

Despite the lack of conclusive evidence to demonstrate what strand of vocabulary knowledge underpins reading, the links (or inter-relations) between language ability and reading success are strongly held. Vocabulary knowledge is still consistently shown to be one of the best predictors of reading comprehension in people without IDs (Muter et al., 2004; Nation and Snowling, 2004; Protopapas et al., 2013). Furthermore, as represented in The Simple View, Stuart et al. (2008) maintain that the integrated and interdependent nature of phonological and semantic processes necessary for good reading require a solid foundation in language comprehension.

It follows that people with IDs who generally have poorer language comprehension (Nash and Heath, 2011), a smaller depth of vocabulary (Henderson et al., 2013) and often shorter memory span (van der Schuit et al., 2011), could find it challenging to access text

for useful understanding. This means that for some, uneven reading profiles may create challenges to successful understanding of information.

1.7.2 Reading and intellectual disabilities

While a search for literature in the area of literacy skills in children with IDs revealed a number of studies, there was less that related to adults. As a group, the reading skills of children and adults with Down Syndrome (DS) have been more specifically researched. Links have been made between their language and literacy skills, and findings also suggest a difference between the processing of written material by those with DS and without IDs. People with DS are a discrete group within the wider heterogeneous population of people with IDs, many of whom have some reading ability. Byrne et al. (1995) demonstrated that all of the twenty-four children with DS between four and twelve years old observed in their study over a two-year period were capable of learning to read single words, despite variation in other cognitive abilities such as memory and language. Nash and Heath (2011) later reported strong existing correlations between literacy skill and language ability in thirteen children and young people with DS when compared to control groups without IDs. Consistent with previous findings from research into the reading abilities of children with DS (Boudreau 2002; Carr, 1995; Laws and Gunn 2002), they found that reading comprehension abilities were lower than those children in their control groups. Importantly, Nash and Heath (2011) identified reading comprehension ability within the DS group to be limited by how well individual words were understood and the ability to retain words in working memory for making inferences. This supports the theory that vocabulary knowledge is key to reading success for many people with IDs.

In line with Nash and Heath's (2011) study, findings from a two-year longitudinal study by Hulme et al. (2012) that compared forty-nine children with DS and sixty-one children without IDs also supported language capacity as a strong predictor of reading success amongst the children with DS. Additionally, Hulme et al. (2012) suggested that children

with DS followed a route to reading success that was qualitatively different to their non-DS peers; one that was eventually more reliant on overall vocabulary knowledge than on phonological awareness. van Tilborg et al. (2014) also concluded that the pattern of literacy development demonstrated by seven year olds with IDs (n=17) was distinct from their peers. They found that IQ measures (which were shown to correlate with vocabulary in children with IDs), and rhythmic ability were stronger predictors of early literacy than other factors such as phonological awareness and word decoding in the IDs group.

Further findings from a systematic review of eight studies into the non-word reading abilities of children with DS by Naess et al. (2012) also supported this outcome. They found that vocabulary knowledge predicted non-word reading ability more strongly than phonological awareness. This was surprising because based on the theory that non-words could not be accessed via the semantic route for whole word reading, it would be hypothesised that the readers would focus on phonological processing to read the non-words presented. Nonetheless, it seemed that the children in studies reviewed by Naess et al. (2012) showed strengths in decoding words at a phonological level. However, this did not explain the variation shown in their decoding of non-words. Variation was attributed to vocabulary levels and although authors acknowledged the role of vocabulary knowledge in reading non-words, they could not explain it. They concluded that for children with DS, the relationship between phonological skills and decoding of words is weaker than that found in children without DS. It might be suggested therefore that while decoding of words for some children (and adults) with IDs, is a strength, they might be relying on cognitive processes involving overall language and vocabulary knowledge that are distinct from the processes used by people without IDs.

The compensatory role of vocabulary and word knowledge to decode words is consistent with evidence of weak phonological awareness skills in children with IDs. Channell et al. (2013) showed that children with IDs (n= 17) had poorer phonological skills than their peers without IDs (n=17) when matched for verbal ability. Findings from a similar study by Levy (2011) compared groups of young people with DS (n=19) and with other IDs (n=19)

and revealed that decoding words was indeed correlated to phonological awareness although these skills were mediated by IQ levels in the latter study. However, evidence has also suggested that people with IDs who experience difficulties with language and with reading comprehension may not necessarily find it as challenging to decode words.

Participants in the Nash and Heath (2011) study were notably good at sight reading vocabulary. This was consistent with Byrne et al. (1995) who described participants with DS as adopting a visual 'logographic' approach to reading single words, although being able to sight read did not equate to having good phonological awareness. Surface level decoding linked to successful whole word recognition is a skill previously identified in people with DS (Nash and Heath, 2011) and has also been demonstrated by Nation et al. (2006) on a more absolute level in participants with autistic spectrum conditions (ASCs). Nevertheless, this differs from deeper level metaphonological (phonological awareness) skills that are linked to sophisticated deep word knowledge and to successful reading comprehension. The ability to manage ambiguity of homonyms and to select the correct meaning of a word within its linguistic context (Henderson et al., 2013) depends on having good metaphonological awareness and sufficient word knowledge. The distinctions made by Protopapas et al. (2013) between breadth and depth of vocabulary knowledge and their differing impacts on reading comprehension are pertinent to the current argument. It follows that a person with DS or an ASC with a wide (but superficial) vocabulary and good decoding skills may be able to read but not have the depth of word knowledge to understand what has been read.

Despite the strong links evidenced between language and literacy and the predictive value of vocabulary in reading, participants' comprehension of spoken language in Nash and Heath's (2011) study was better than their levels of reading comprehension. This suggested that understanding what had been said was less challenging than understanding what had been read. The ability to understand spoken language did not therefore transfer into understanding written language despite an apparent ability to 'read'. Arguably, the process of reading requires a number of skills and effort must be

expended first at the decoding level. This could detract attentional resources away from constructing meaning from the text and would explain why listening and understanding was easier for participants than reading and understanding.

Further research into reading abilities of the wider population with IDs supports the view that reading is a complex process that cannot be causally attributed to language comprehension alone. Vandereet et al. (2010) reported varied and uneven literacy profiles of strengths and weaknesses as might be expected with a heterogeneous group of participants. (They analysed the language of thirty-six children with IDs in the Netherlands over a two-year period). Again, one of the biggest areas of vulnerability in comparison to the non-ID control group in their study was reading comprehension. Children with IDs were shown to develop vocabulary (and semantics) more slowly than their peers without IDs. Later, van der Schuit et al. (2011) demonstrated how the relative sparseness of vocabulary in fifty children with IDs was shown to inhibit their subsequent development of grammar from around the age of 4 or 5 compared to those without IDs. The authors concluded that the participants with IDs needed to achieve a larger 'critical mass' (2011: 1892) of vocabulary than the control group without IDs before the same activation processes were triggered to achieve similar levels of syntactic recognition and understanding of spoken language.

It has been demonstrated that difficulties with understanding text through reading for people with IDs can occur at both decoding and semantic levels. The evidence reviewed showed that strong vocabulary knowledge underpinned good reading comprehension for this population, and this finding ran consistently throughout the literature. Without a good vocabulary (both breadth and depth), readers with IDs may experience challenges in making inferences from text and this could lead to the slower activation of concepts, weaker spreading or linking of those activations and /or problems with the integration of information that is external to the text. Findings have also indicated qualitative differences in the ways that processing skills are used for reading by groups with IDs compared to groups without. In addition, it might be argued that vocabulary knowledge is

itself vulnerable to the influence of other intrinsic and extrinsic factors. The following paragraphs consider some of the intrinsic cognitive functions that influence reading ability

1.7.3 Cognition and reading

Written information is likely to present challenges to anyone who experiences difficulties with specific or generalised cognitive functions (Channel et al., 2013; Levy, 2011; van Tilborg et al., 2014). This will include a large sector of the population of adults with IDs. Executive functions are crucial to the development of literacy skills, and affect reading comprehension. As mentioned, working memory (Nash and Heath, 2011; Hulme et al., 2012), flexibility, attention, the ability to select or inhibit information and responses, perceptual skills, and motivation, can be determined as intrinsic factors, and are influenced by extrinsic circumstances (Henderson et al., 2013). Uneven profiles of cognitive skills have been shown to contribute to low reading comprehension in studies that involved participants with IDs.

McNamara and Magliano (2009) documented the shift in overall focus from reading as a set of discrete functions to considering conceptual understanding of text as a series of interactive processes within a cognitive psycholinguistic model. This centrally includes the role of memory. Specific working memory (WM) and long term memory (LTM) skills have been shown to predict reading comprehension. Indeed, WM capacity was demonstrated as a stronger predictor of reading comprehension than either vocabulary or decoding in a study of forty-eight primary school children without IDs (Seigneuric et al., 2000). Memory impacts on a reader's ability to recognise words, retrieve their meaning and then make inferences to situate their understanding of those words in a real world context. Thus it can be argued that memory as part of cognition plays a strong role in the construction of relevant meaning within any communication event.

Whilst evidence is meagre, differences have been demonstrated between groups with and without IDs in terms of links between cognitive processing and reading. These are similar to the differences identified above in processes of language development and vocabulary skill in relation to reading across participant populations, Numminen et al. (2000; 2002) studied WM processes in adults with IDs in Finland. They used a battery of tests with forty-six and twenty-six participants with IDs in these studies respectively to uncover possible links between cognition and memory. Structures of WM were revealed as falling into two categories: a general WM category which was related to intelligence levels, and a phonological WM category which was not. They concluded that good general WM was more likely to predict achievement in academic skills such as reading and writing than good phonological WM. Moreover, they proposed that vocabulary acquisition in people with IDs was more dependent on general WM and IQ than in the general population.

It would appear that Numminen et al. (2000; 2002) made a connection between general WM, vocabulary development and reading skills in people with IDs. Underlying these connections was the influence of general WM (rather than phonological WM) on the ability to develop a strong vocabulary which is consistent with the earlier findings from Seigneuric et al. (2000) who established the similar outcomes with participants who did not have IDs. This implies that IQ and vocabulary affect reading comprehension. Possibly, activities to strengthen general WM backed up with a focus on expanding general knowledge might influence word learning and improve reading comprehension for people with IDs more effectively than a focus limited to phonological training that may only promote better surface level decoding.

Numminen et al.'s (2002) study showed a further qualitative difference in the way typically developing children (N = 24, ages 3-6) responded to WM tasks compared to adults with IDs (N =24 age < 60) who were matched for intelligence scores. Tasks included measuring digit-span (both backwards and forwards), non-word repetition, visuo-spatial ability, as well as reading, writing, number and vocabulary skills. While the children were

better at accessing online WM (that did not rely on a well-developed knowledge base) for a range of tasks, the participants with IDs were more skilled at using their wider knowledge base to access semantic information using LTM particularly in relation to tasks that involved language. Numminen et al. (2002) suggested that the participants with IDs were able to use their wider vocabulary knowledge to compensate for WM ability and this could have supported their performance in the non-word repetition task.

Similar findings (van Wingerden et al., 2014) demonstrated significantly higher vocabulary abilities in forty-nine children with IDs when compared to their non-ID peers (n=21) matched for cognitive levels. Matched for chronological age, however, the discrepancy in vocabulary was not evident. It seemed that the children with IDs who had more life experience had a wider vocabulary than younger children of the same cognitive level. Despite this positive factor, Bowyer-Crane and Snowling (2005) revealed that nine year olds with poor reading comprehension found making inferences from text more problematic than a control group of average readers. They reasoned that the poorer readers found it more demanding to apply real world information to the text while they were reading and this hindered their ability to make inferences. These studies demonstrate the qualitative differences between people with and without IDs in using WM, and the importance of life experience and its contribution to making sense of both written and spoken information.

Skilled readers also use continual updating strategies to develop their thought pathways while reading a text from beginning to end. This requires flexibility of thought governed by executive function and a good WM to aggregate and integrate new information with the old. Not surprisingly, Carreti et al. (2010) discovered that adult participants with IDs (n=25) found updating information while reading much more difficult than their peers without IDs. Successful efficient processing also requires particular visual perceptual abilities, alongside good vision, to make sense of what is presented on paper (figure-ground perception, colour processing, scanning and other learned textual skills i.e. following bullet points and understanding tables or columns). Treisman and Gelade

(1980) originally called this 'feature integration theory'. They considered that attention was a requirement for efficient processing and argued that items were processed in an integrated way through pre-attentive processing where different features were located in parallel or serially at a sub-conscious level, and then recognised and interpreted. As previously discussed (p34), Williams and Hennig (2015) have demonstrated that people with IDs were more likely to process items on ER websites sequentially, but no other research into the nature of visual and cognitive processing of ER information by people with IDs was found to corroborate these findings.

To summarise, in addition to clear evidence for the impact of language capacity on reading comprehension, multiple intrinsic factors including perception and attention also affect how well written information is understood by people with IDs. These are crucially underpinned by WM which facilitates inferential processing. It follows that such findings might be applied to reading and making sense of information by readers of material in an ER format. A complex picture has resulted from a review of the evidence that reading, language and cognition are variously employed in a process that might well be qualitatively different for adults with IDs than those without. Extrinsic factors that can further shape the intrinsic capacity to understand information will be discussed in the following section. These include the ER material itself, human interaction and the influence of other environmental factors.

1.8 Extrinsic factors of influence on understanding

One of the main extrinsic factors under scrutiny in this research is the linguistic infrastructure of ER material that has been simplified and adapted for its target audience. Features such as images, font size, layout, colour, the topic covered, the language used, the length of the document and whether authorship has involved co-production could all contribute to how well meaning is constructed in the final document. Often, however, the information in ER health documents is communicated through interactions with other people. Tuffrey Wijne and Hollins (2014) reported on the use of ER in acute care settings

in a national patient safety study. They found overall a lack of adequately adjusted services being implemented for people with IDs in hospital care and stated the need for a flagging system that identified the appropriate adjustments required. Examples included ER material, longer appointments, changes kept to a minimum and the need for a carer or advocate to be present. Adjusting communication to the patient's language capacity was possibly implied in this article, although not specifically mentioned. It might be argued that knowledge of the receptive language abilities of a patient could be critical to the successful outcome of most of the suggestions listed by Tuffrey Wijne and Hollins (2014) in healthcare settings. This is particularly relevant to ER material, listed here as a stand-alone adjustment that could be provided without assistance or support for understanding. There are a number of other extrinsic factors that can play a part in the construction of meaning and building relevance from ER material, without which crucial information risks being misunderstood or not understood at all. Human mediation and instruction fall into this category.

1.8.1 Reading instruction

As shown, it is clear that cognition plays a role in reading success, both in recognising words in the text and in reading comprehension (Caretto et al., 2010; Henderson et al., 2015, Numminen et al., 2000; 2002; Vandereet et al., 2010). Unlike the acquisition of language, the acquisition of literacy is often thought to be a taught skill, usually established through formal education. Various instructional methods for teaching reading to children and adults with IDs have been investigated. As described, some subscribe to a social practice approach (Morgan and Moni, 2008; Young et al., 2004) and these cases, which build on strengths, prior knowledge and interests, have been reported to be successful. Small case series studies have further examined the effect of whole word sight reading (Alberto et al., 2010) and the use of a modified system of prompting described as minimally intrusive (Browder et al., 2013). Despite the small participant numbers, both studies reported improvements in participants' reading comprehension. Alfassi et al. (2009) implemented a reciprocal reading process with thirty-five adults with IDs over

twenty-four sessions. This involved a structured discussion about the text using a summary, the clarification of any information, and the shared formulation of questions. They reasoned that repeated and shared dialogue would help readers to monitor their own understanding. Again, the group who received this reading instruction achieved significantly better on reading comprehension measures.

Many adults with IDs who have never 'learned to read' can recognise and respond to words in their environment for example, a familiar street sign, the name of a football team, or their own name on an envelope (Morgan and Moni, 2008). The consideration of literacy as a social practice (Papen, 2009) supports the development of literacy skills within a person's life context. By doing so, it is easier for a reader to capitalise on the relevance (Wilson and Sperber 2002) that a document or interaction offers and meaningful understanding is more likely to follow. For example, Morgan and Moni (2008) explored motivating readers with IDs through the personalisation of reading material based on individual interest and their individual current social contexts. Sharing stories, enriching spoken interactions, giving more choice and creating enjoyable opportunities to read have also been found to promote literacy development (Browder et al., 2006; Ricci, 2011) and to increase reading success (Young et al., 2004).

Despite the emphasis in commonly used guidelines for producing ER material that is easier to read, constructing understanding from an ER text is not represented in the empirical research literature as learning to read, but as a route to gaining information (Owen, 2006, Poncelas and Murphy, 2006; Hurtado et al., 2014). As mentioned earlier in this introduction (Jones et al., 2006) the average reading abilities of people with IDs in the UK was estimated to be around age six. Thus human literacy mediation has evolved as a natural development to bridge support for understanding. The common factor in the research studies mentioned above is the extrinsic influence of literacy instruction or mediation on understanding. The nature of human literacy mediation is crucially important in constructing understanding and in gaining new knowledge for learning,

particularly within population groups such as those with IDs who find written text challenging.

1.8.2 Literacy mediation

Papen (2009) proposed the term 'literacy mediation' to describe the individual support given to facilitate better understanding of written information. It can be seen as one primary extrinsic factor that might contribute to overcoming individual difficulties inherent in processing and understanding text for people with IDs. West (1978) and Beck (1984) identified attentional resources at a reader's disposal and how mediation interacts with these. They demonstrated how readers allocated attentional resources to the different processes required for reading (conscious and sub-conscious) depending on the reader's literacy profile. Walmsley (2013) has also described how the role that other people play in the construction of meaning can shape the outcome. With the addition of literacy mediation, the agency for directing attentional resources might remain with the reader, or agency could be removed from the reader and held by the mediator creating an uneven power dynamic. This is more likely to happen within a goal-focused task if the mediator has their own agenda (McNamara and Magliano, 2009). Thus power balances in such interactions could affect the way a text is understood. The effects of extrinsic textual, social and environmental contexts and how they interact with intrinsic factors are explored in the following sections.

Literacy mediation carried out with people with IDs by carers, family members, or other professionals is arguably likely to be limited in its systematic delivery and variable in terms of the time spent together developing knowledge of information. The area is not well researched in terms of evaluating the quality of mediating interactions.

Notwithstanding, communicative engagement has been identified as central to understanding information within a framework of health literacy (Chinn 2014; Rudd 2003). An equally high value has been placed on flexible face to face mediation with ER

material in participative research and studies with co-production groups (Owens, 2006; Rogers & Namaganda, 2005; Ward & Townsley, 2005). This is further reflected in Mander's (2013) 'triangle of accessible information' which includes the mediator, who has personal understanding of the resource information, the resource (which provides a focus for joint attention), and the user. Mander (2013) used conversation analysis (CA) (Ten Have, 2007) in a small single case series to investigate four interactions between people with IDs (n=4) and their designated community nurses where ER material was the shared resource. Transcriptions of the recorded interactions revealed that how well people understood information was dependent on the level of communication knowledge, skill and communicative insight of the mediator, the goal of the interaction and the context in which it was delivered. This suggested a reliance on the mediator for successful construction of meaning, which frequently implicated the supporting role of the primary carer (e.g. support staff, carer, parent, teacher).

In relation to the effort involved in building joint understanding, Grove (2014) demonstrated the variation in possible interpretations of images, by showing different representations of the concept 'meeting'. These included: a complex coloured photo of a woman on a stage singing with people behind her, a line drawing of several stick people around a table, a drawing of a stick man talking to three seated stick people and a symbolic representation of a spiral notebook with a photograph on it of people around a table. Without clearly establishing the meaning in context, each of the images could be interpreted to represent something different, either by the mediator or by the target reader. Specifically in relation to ER material, images that make sense to one person could be mis-interpreted by another.

The intended interpretation of the author and whether the inferences provided were explicit or merely implicit was key to the inferential understanding of the image for Grove (2014). According to Wilson and Sperber (2002), only the most explicit inferences, either textual or through images require minimum effort. However, making inferences explicit when faced with complex concepts might involve deeper work around these to ensure

that cognitive gain is at least on a level with effort. Grove (2014) showed how complex concepts such as 'citizenship' might meaningfully be understood. By working together within a group or individual's zone of proximal development (Vygotsky, 1978 (see p. 37)) and building on recall from past experience or knowledge, a system of definitions was developed by Grove (2014) through discussion and consensus. This subsequently provided scope for creating new life experiences as a means to understanding and consolidating written information about 'citizenship' such as taking part in voting. It appeared that mediation processes as a main extrinsic influence on understanding could hold substantial power over how meaning is constructed and what is ultimately understood.

1.8.3 Expanding knowledge and understanding

The idea of expanding knowledge and understanding is just emerging in research on the way that information is communicated with people who have IDs. Ferguson and Murphy (2014) demonstrated how increasing capacity for knowledge through tailor made training sessions with small groups was more successful than using ER health information leaflets. Twenty-eight adults with IDs were involved in workshops to develop understanding about the specific type of prescribed psychotropic medication that they took. The study focused on developing knowledge about the possible side effects and consequences of taking or refusing medication for long term mental health conditions. Baseline knowledge was measured before and after the three training sessions and final measures demonstrated a significant increase in knowledge which led to more robust capacity to consent. Evidence suggested that increased capacity and knowledge in this study led to increased choice, and reduced risk in participants. By acknowledging that participants could not immediately understand or access a concept, space was created for adult learners to increase their self-determination and voice through increasing literacy skills and developing understanding of new concepts.

Several factors were central to Ferguson and Murphy's (2014) success. Continuity of support was evident. Explanation was not a one-off conversation, but a series of meetings and activities where health and social care professionals met with the group for discussion. The team were able to become familiar with participants and to develop communication and materials that were naturally adapted to fit with group members' individual levels of receptive language for optimal understanding. Opportunities to check that information had been understood were built into follow-up sessions. Finally, the task was goal orientated (the focus was on making informed decisions about taking medication), and group members were encouraged to take responsibility for these, constructively controlling their own attentional resources (with support) to do so. Other extrinsic factors such as fatigue, whether someone was negatively affected in certain settings (such as a clinic or hospital), or whether noise, or general health was interfering with the ability to process information were also more easily monitored when human mediation was responsive and familiar and when several opportunities were available for interaction. Ferguson and Murphy's (2014) study demonstrated the complex and time-consuming processes involved in constructing meaning from written information and the value of structured, responsive and repeated literacy mediation.

As previously argued, Relevance Theory, developed by Sperber and Wilson (1986) provides a theoretical framework of communication and cognition that helps to unify the various intrinsic and extrinsic aspects identified in the current study that contribute to how information is understood. From a sociolinguistic perspective on communication, Sperber and Wilson (1986; 1996) argued that people naturally engage most effectively with information that is easiest to understand and that holds the most relevance for them, either spoken or written. The theory was based on two main claims: 1. Human cognition tends to be geared to the maximisation of relevance and 2. Every act of ostensive communication communicates a presumption of its own optimal relevance (Sperber and Wilson, 1996:261). They proposed that within any act of communication, both parties continually seek out points of relevance for themselves within the context of the interaction and this will be influenced by who is conveying the information, the topic being discussed, and the manner in which it is expressed.

To achieve relevance out of an interaction effectively requires skills (such as reading and communication) and knowledge of how to interact with the medium provided (the interpretation of language in text or from a human being). The process of constructing meaning is shaped by the form the message takes (the ER material and human support), and by a person's cognitive abilities and prior experience and knowledge. According to Sperber and Wilson (1986), information (spoken, written or symbolic) that requires the least effort will have the biggest and fastest cognitive effect and will therefore be most successfully understood. They have argued that subject matter is important because the perception of possible cognitive gain through processing familiar information (as opposed to unfamiliar information) contributes to maximising its potential relevance. The process of gaining particular information needs to balance or outweigh the effort involved, or it could be deemed irrelevant, superficially considered and then discarded. Relevance theory (Wilson and Sperber 2002) shares elements with the constructionist models of communication processing previously identified by Kintsch and van Dijk (1978). Successful meaning construction relies on being able to apply cognitive skills such as memory and conceptual understanding, executive functions and language capacity. Both Relevance Theory and constructionist models maintain that any extrinsic contextual clues relevant to understanding at the point of processing information will affect how and what is understood.

Guidelines for ER information specified that 'changing the way we write and present information can make it easier for everyone to understand' (MENCAP 2002:2). Similarly, Change, an advocacy organisation dedicated to the co-production of ER material explained in their ER guide that 'language is very important because it helps people to take control of their lives. It can prevent people from getting the information they need to make choices'. While these comments demonstrate awareness of the extrinsic role of language used in text, the emphasis on superficial simplification within ER guidelines remains and there is little mention of expanding knowledge. ER material based on such guidance is therefore open to challenge in terms of its effectiveness in the construction of understanding.

A further criticism levelled at ER information is that it does not take into account the cognitive level of some service users who might not have the ability to understand complex concepts (Walmsley, 2013). Over the last 12 years, the DoH in the UK has published policy and advice documents in ER format. These include white papers (DoH, 2012, Caring for our future 3E/N), health information (DoH, 2009, MRSA Screening 2E/N), consultation papers (DoH 2009 Mental health consultation 24E/N), and reports (DoH, 2012, Winterbourne View 44E/N). Many of these contain information that is complex and abstract. It is therefore difficult to represent this faithfully in a simplified ER version while conserving its relevance for readers who find text difficult to process.

Hurtado et al (2014) demonstrated how split attention between pictures and text created a situation where more effort was required from participants with stronger reading skills because they were trying to process and integrate two types of input simultaneously. Somewhat counter to expectation, they understood less than those with more limited reading skills when presented with the same task. Hurtado et al., (2014) argued that readers with poorer reading skills were not distracted by the text and focused their effort more on the images while listening to the information being read, whereas the good readers were working to both decode and make sense of the text, relate this to the pictures and listen to the reader.

When effort outweighs cognitive gain the person processing the information is liable to decide that there is little value in continuing to pursue the task. Ideally an optimally relevant ER document is one where the cognitive gain effected by understanding the information should outweigh the effort of trying to understand it. Not surprisingly, the variability in individual combinations of intrinsic and extrinsic factors that contribute to the construction of meaning suggest that any ER universal design is untenable. Indeed, it suggests that reliance on a document alone is untenable. Working within the premise of relevance imparts a flexibility to the individual process of constructing meaning and shifts the emphasis from making changes in a document to making changes in how the information in the document is communicated.

The construction of meaning from any information involves the interplay of intrinsic and extrinsic influences. These uniquely shape the relevance of any spoken or written information for the individual. Effort required from the reader, their motivation and the quality of mediation offered are suggested as strong factors in the success of understanding written information. As yet, there is little evidence to suggest that the superficial extrinsic changes made through the process of simplifying documents for ER purposes adds to that success. Furthermore, while evidence has demonstrated the value of human mediation in meaning construction, the quality and nature of the interactions involved have been shown to affect the outcomes for understanding both positively and negatively.

1.9 Summary

The political and social climate from which ER material emerged placed empowerment, equity and social model principles on the agenda. It aimed to reduce the challenges faced by people with IDs in understanding a range of issues that continue to affect them today. More specifically, it has been used to convey a variety of information to its target audience on issues related to health and social care. The risks of not understanding information about health and not being able to apply that information in practice are high for people with IDs, and particularly for those who experience difficulties with reading and language. As explained, following a number of legal enactments initiating the concept of reasonable adjustment, the Accessible Information Standard (NHS England, 2015) has made it a legal requirement for all health and social care organisations to put support in place to facilitate the understanding of health information for anyone that needs it (p. 26). One of the routes to achieving this was through the use of ER material. Production has gone from strength to strength and there is now a battery of private, local and national enterprises established in the U.K. that charge for their ER service. Despite apparent demand, there continues to be very little evidence base to demonstrate what elements of ER presentation or what aspects of language simplification help to build *understanding* of health information for the reader.

A number of intrinsic factors that influence how successfully people make sense of information have been identified through a review of related literature. Elements included those associated with executive function and reading skills. Evidence has demonstrated that language capacity and vocabulary knowledge in particular, along with WM underpinned these processes for the effective construction of meaning. Additional to the variable extrinsic influence of the ER documents themselves, the potential of human mediation and interaction for shaping the understanding of written ER information was also reinforced. Given that the drive for ER production has both financial and human resource implications, the need for a robust evidence base is called for. At present, a market for ER material exists that is driven by design rather than by evidence for its positive influence on comprehension for people with IDs.

1.10 Research objectives

The current research aimed to establish what characterises ER material in the UK and to present evidence that might serve as a foundation for future production and implementation guidance. It aimed to establish trends in presentational features in ER material and in their equivalent N-ER versions. This was anticipated to provide a valid sample of production trends developed over a ten-year period. Similarly, it aimed to establish the most commonly used linguistic features and conventions evident in the simplified language of ER material in contrast to the original N-ER versions. Information was gathered on the salient linguistic features evident in ER material that were likely to affect understanding. Particular attention was levelled at the cohesive devices used and how they affected overall coherence of the texts. Establishing the nature of the language in ER documents through linguistic discourse analysis was ascertained as a further essential goal, necessary to evaluate text cohesion more closely. The presence and absence of patterns of cohesion through the use of repeated words and referents that provided explicit information (clearly stated and unambiguous) or implicit information (requiring inference) were further identified and compared. Other unintended outcomes such as unequal power balances were also compared with a view to identifying

approaches that might minimise apparent inequalities. Evidence from these three text-based studies were expected to generate tangible suggestions for producing more cohesive and responsive ER material.

Finally, an empirical study aimed to establish an evidence base for the use of simplified text and literacy mediation with people with IDs. Consistent with Relevance Theory (Wilson and Sperber 2002) it might be assumed that users of ER material gather evidence from the ER document, the context, their immediate environment and their background knowledge to construct relevant meaning. While this relies on an individual's cognitive abilities and language capacity, the process also relies on a reader's pragmatic skills to assimilate multiple sources of information in real time and to make sense of it. Using Relevance Theory as a basis for argument, a number of possible strategies and some guidance for how ER literature might be used in practice to construct meaningful understanding of information was the anticipated outcome.

This research aimed to address the overall research question: how effective is health-based ER literature in contributing to the construction of meaning for people with IDs? The investigation was conducted via a series of four studies that examined discrete but related areas of ER information and its use. The design of each study, the aims and research questions are summarised below for the reader. The full title for each study is provided followed by the short title which is used when referring to individual studies within the text of this thesis.

Study A: A survey of 'Easy Read' and 'Non-Easy Read' documents published by the DoH, UK.

Study A: The Survey was a descriptive survey comparing ER documents sampled from the DoH website published between 2000 and 2012 with their N-ER versions. The two-fold aim of the study was: to investigate guideline features (DoH, 2010; MENCAP, 2002; Inclusion Europe, n.d.) as they were applied to DoH ER literature and to compare these

with features used in the equivalent N-ER documents. There was one main research question: How does ER material compare to its N-ER comparators with reference to established categories in National and European Guidelines?

Study B: Making health information ‘easier’ to understand: a comparison of the linguistic features of UK DoH 'Easy Read' documents and their ‘Non-Easy Read’ counterparts.

Study B: Linguistic Analysis involved a comparative survey of linguistic parameters of texts sampled from the DoH documents surveyed previously in Study A. It aimed to establish the critical differences between the linguistic features of DoH documents designated as ER and N-ER. This study addressed the questions: a) How do ER and N-ER documents differ in terms of the linguistic features used to enable surface and deep level understanding of text? and b) What features specifically exemplify these differences?

Study C: ‘Easy Read’ – simplification or reduction? Critical differences in the discourse of UK DoH 'Easy Read' literature and their ‘Non-Easy Read’ equivalents.

Study C: Discourse Analysis was an in-depth, qualitative analysis of textual discourse. It aimed to examine the critical differences in the discourse of DoH ER literature and their N-ER equivalents. A systematic qualitative linguistic analysis was undertaken to identify the subtleties conveyed in N-ER texts compared to those designated as ER. How textual cohesion affected overall coherence of the texts, the language chosen to represent processes and people, and the author’s stance were the areas of focus for investigating the following central questions: 1. How is the overall coherence of the original texts maintained in the ER versions (e.g. contextual relevance and informational salience)? 2. To what extent do ER versions replicate the representation of reality provided in the N-ER versions of texts (e.g. levels of agency and responsibility assigned to key stakeholders)? 3. How do they replicate the author’s original level of engagement with their readers (e.g. forms of address and power relationship)?

Study D: The effects of linguistic simplification and mediation on the comprehension of 'Easy Read' text by people with intellectual disabilities: a randomised experiment.

Study D: The Easy Read Task. A 2 x 2 between subjects design was used defined by two levels of linguistic complexity: simple or complex, and literacy mediation: present or absent. Sixty adults with IDs participated. The study aimed to demonstrate to what extent the linguistic simplification of ER material and/ or support from human literacy mediation contributed to the construction of meaning for participants. Specifically, the study aimed to answer the question: What effect does linguistic complexity and mediation have on the reading comprehension of ER information by people with IDs? It further investigated the questions: How do receptive vocabulary skills and general reading ability affect reading comprehension of ER information?

Each study will be presented separately over Chapters two to five consecutively. The first three (Studies A, B and C) were focused on investigating paper-based ER and N-ER material. Background information and separate sections addressing study limitations and discussions are provided for each of these three studies. Each one naturally emerged from the findings of the previous study. In contrast, the discussion for Study D is presented within the overall discussion section in Chapter six in synthesis of the full thesis. Discussion points and threads from the previous three studies (A, B and C) are re-traced in Chapter six and contribute to the final debate.

The next chapter is entitled Study A: A Survey of Easy Read and Non-Easy Read DoH Documents. Consistent with the organisation of all four studies, it presents an account of Study A, covering background to the study, methodology, results and discussion before establishing the implications of the findings and providing a rationale for the next study in the series.

Chapter 2. Study A: A Survey of ‘Easy Read’ and ‘Non-Easy Read’ DoH documents

Study A: The Survey was about capturing the main distinctions between ER and N-ER documents produced by the DoH over a twelve year period from 2000 to 2012. It aimed to identify the differences in surface level language, presentational features and production trends between ER and N-ER material.

2.1 Background to The Survey

The background that follows draws on literature discussed in Chapter 1. Relevant topics that have been previously addressed will be given deliberate correspondence with Study A, The Survey. Key initiatives and evidence that have a direct bearing on the topical focus of this study will then be reviewed.

Reference has been made to the current proliferation of available ER material produced for people with IDs, the number of production teams and companies involved, and the range of advice given in various published guidelines (Section 1.5.1, p. 29). Moreover, informal reviews of selected DoH ER material with advocacy groups in Norfolk (Buell 2015) revealed that it was both received and approached in distinct ways. Observations were made in six different day care settings and advocacy group meetings. A range of printed DoH ER material was handed out to people with IDs who showed an interest (usually in a café setting or other informal environment). They were invited to say what they thought about the material and were allowed to keep the document if they declined the invitation to discuss it. Some flicked through it quickly or scanned it, others wanted to talk about the pictures, some read the words and others set it aside for later or said they would keep it to show someone at home. Still others asked what it was about and some who were offered refused it. This ER material was presented with no expectation or end goal, and as described, the range of initial responses varied.

To some extent, the variable responses observed in these informal settings could be said to reflect diverse preferences. This corresponds to the wide range of different published ER products (identified in Section 1.5.2, p. 32) as producers strive to meet the needs of a heterogeneous population. From the user perspective, it did not seem that there was a one-size-fits-all solution for a universally well-received ER document. Given the high number and unique perspectives of production teams, the range of different guidelines to support the process and the variety of resources available to meet differing communication and literacy requirements, it is perhaps to be expected that ER documents will vary widely in style, content and quality even within the range produced by one entity over a period of time.

In summary, variation and diversity in preference and production continue to be supported by evidence from user groups (Section 1.5.6, p. 46), and a diverse range of ER products has endured despite the persistent aims to develop published guidelines with standardised formulas for creating ER material (The Accessible Information Standard; NHS England, 2016).

'Easy Read' guidelines.

A long list of available published guidelines for producing ER material has been given in Section 1.5.1, p. 29. Of those that focused on modifying information for people with IDs or other communication disabilities, the most commonly cited guidelines are those by MENCAP (2002), a national charity for people with intellectual disabilities and their families, the DoH (2010) and Inclusion Europe (n.d.). These have been used to provide an overview of the current advice for the development of ER material.

A review of the guidelines from MENCAP (2002), and from the DoH (2010) have previously featured in a survey of ER guidelines in the U.K. This was carried out by four final year students on the BSc (Hons) speech and language therapy programme at the University of East Anglia as part of their third year dissertation project (Bunning et al.,

2011). This work entailed the systematic identification of similarities and differences across the two sets of guidelines, and features were grouped according to homogeneity. A review was carried out separately by the two pairs of students before a final appraisal was undertaken with the project supervisor. Any disagreements in the organisation of items were debated and the final set of categories were achieved through consensus. For the purposes of the current Study A: The Survey, this framework of categories and their content were inspected and appropriate adjustments were made to include advice also provided by the European Guidelines (Inclusion Europe n.d.). Recent draft guidelines in circulation from NHS England (2016) in relation to the Accessible Standard for Information are not yet published or available in the public domain. Despite the addition of a strong focus on promoting co-production, the Accessible Standard guidelines continue to provide similar advice to the guidelines that were included in the review as described above. The five common categories that emerged were: language, layout, images, typography and production. Core advice from the three sets of guidelines (DoH, 2010; Inclusion Europe, n.d.; MENCAP 2002), organised by category is shown in Table 2.1.1 Summary of guidelines below.

Table 2.1.1 Summary of guidelines

1. Language	<p>Use familiar words; write as you speak</p> <p>Use numerals not words</p> <p>Use short clear sentences</p> <p>Use active sentences (not passive)</p> <p>Use only full stops (no other punctuation) (+ &!)</p> <p>Avoid abbreviations: use 'half' not 1/2)</p> <p>One subject or topic per page</p> <p>Avoid jargon</p> <p>Use natural spoken language</p> <p>List difficult words or highlight/box</p> <p>Explain difficult words</p> <p>Use whole numbers /Put dates in full</p> <p>Use props</p> <p>Use present not past tense</p> <p>Be consistent in use of words</p>	<p>Avoid sentences longer than 15 words</p> <p>Avoid contractions, apostrophes and semi-colons</p> <p>Use proper names not pronoun (he, it)</p> <p>Avoid metaphors</p> <p>Avoid words from other languages</p> <p>Avoid questions</p> <p>Use direct 2nd person 'you'</p> <p>Only give important information</p> <p>Give one idea per sentence</p> <p>Examples to explain things</p> <p>Order information in an easy way</p> <p>Group all information about same topic</p> <p>Repetition is better than variety</p> <p>Avoid negative sentences</p>
2. Layout	<p>Use bullet points</p> <p>Don't split words over 2 lines</p> <p>Don't split sentences over 2 pages</p> <p>Avoid columns</p> <p>Split two-line sentence at natural pause</p>	<p>No justified text</p> <p>No text indentation</p> <p>Avoid narrow margins</p> <p>Avoid footnotes</p> <p>Use footers/ headings to orientate to topic</p> <p>Sufficient space and box if form filling</p>
3. Images	<p>Ensure consistent use</p> <p>Avoid pictures with no relevance</p> <p>Pictures on left, words on right</p> <p>Don't float text on or across picture</p> <p>Avoid use of children's pictures for adults</p> <p>Avoid cartoon pictures, maps, charts</p> <p>Photos do not photocopy well</p> <p>Ensure a clear image to text relation</p> <p>Specific advice on symbol use (e.g. Widgeit)</p> <p>Link words and pictures together</p>	<p>One picture with each main idea</p> <p>Represent population diversity</p> <p>Avoid too many pictures</p> <p>Large clear simple pictures in colour</p> <p>Avoid words in pictures /words over pictures</p> <p>Avoid pictures with too much in them</p> <p>Use simple graphs and tables</p> <p>Specific advice on photo use</p> <p>Different people like different pictures/ photos</p> <p>Show times with clocks (12 hour)</p>
4. Typography	<p>Clear typeface (e.g. Arial)</p> <p>Type size point 16+</p> <p>Clear headings</p> <p>Writing stands out on background</p> <p>Avoid green background</p> <p>Avoid white type on black background</p> <p>Use bold, not italics, not block capitals</p> <p>Colour code sections and index</p> <p>Avoid special symbols</p>	<p>Bigger font for headings</p> <p>Avoid traffic light colours in borders</p> <p>Alternative colour if preference</p> <p>Avoid negative symbols</p> <p>Type size point 14+</p> <p>Avoid colour type</p> <p>One font throughout</p> <p>Avoid type too light, too close, or special features</p>
5. Production	<p>Avoid shiny paper</p> <p>Use book format (large A5 size)</p> <p>Use alternative formats (DVD/ CD)</p> <p>Check with audience</p> <p>Page numbers</p> <p>Use less than 100 pages</p>	<p>Use less than 20 pages</p> <p>PDF version</p> <p>Matt paper</p> <p>Read it aloud</p> <p>Number pages "2 out of 4"</p>

Many of the points shown in Table 2.1.1 were specific, directive instructions such as ‘put dates in full’, ‘use bullet points’ and ‘avoid questions’. Other suggestions were open to interpretation and used terms that did not have defined parameters, such as ‘explain difficult words’, ‘use short clear sentences’ and ‘ensure a clear image to text relation’. The properties ‘difficult’, ‘short’ and ‘clear’ could be subjectively applied in different ways to ER material by a range of producers depending on the topic and their own style, beliefs and preference. The established categories and associated features in Table 2.1.1, defined the basis for the sub-categories and features evaluated in Study A: The Survey and these are itemised in Section 2.3 under The Survey Method.

Valuing People and DoH ‘Easy Read’

Guidelines such as those summarised in Table 2.1.1 developed out of the gradual increase in grass-roots production of ER material. The difference made by the inception of Valuing People (2001) can be tangibly traced. Walmsley (2010) compared two White Papers; Better Services for the Mentally Handicapped (Department of Health and Social Security 1971) and Valuing People (DoH 2001). The former was written in formal language with no images, whereas the latter was presented with coloured pictures, well-spaced simplified language and accompanied by an audio version. The Valuing People publication had also gone through a wide consultation process which had probably not been the case for the other document. While Walmsley (2010) commended the changes represented in the new Valuing People document, she also questioned whether they expanded conceptual understanding for the target audience or whether the changes made were only superficial.

The DoH have continued to produce documents in ER format and these appear to have been routinely circulated nationally to local advocacy groups and other organisations. Prior to March 2013, a range of DoH ER documents were easily found through any search on the DoH website that used ‘easy read’ in the search engine. Most were easily identifiable along with their N-ER versions and quickly and easily downloaded. These included all of the backdated documents relating to Valuing People: consultations,

strategy reports, information on education policy, employment policy and health. There were also documents relating to critical events such as The Winterbourne View case and information about checking for the MRSA infection. However, from March 2013, all government websites were disbanded in favour of a larger merged government website: gov.org. The same ER documents were subsequently more difficult to find or download from the website. Study A: The Survey has focused on DoH literature for two main reasons. As both Rudd et al. (2103) and Chinn (2014) have explained, understanding information within health can be critical to reducing health risks, living longer and living well. DoH documents disseminate a wide range of important and relevant information with a national reach and as such should provide a benchmark sample of the ER product as used in health and social care in the UK. The birth and growth of ER material has changed the face of public communication with people with IDs in particular. Documents created under the auspices of the DoH thus provided a body of pivotal ER literature still in circulation on which to focus a survey of the language and presentational features used in ER and N-ER documents.

Characteristics of 'Easy Read' documents

With some overlap and similarities in the advice provided in the published guidelines identified in this chapter, it might be expected that similar profiles of characteristics would be found in the ER documents themselves. Nonetheless, there is little evidence of current trends and commonalities within health-related ER material published internationally or in the UK. As previously outlined, (Section 1.5.6, p. 46), there was an overall preference expressed for the use of images of some sort (with the caveat that one person's choices were not always understood by everyone), and subsequent verbal reports by Oldrieve and Waight (2016) have suggested that some users also found the use of pictures childish. Preference for large font was also widespread (Owens 2006; Rogers and Namaganda 2008; Williams and Hennig 2015). Bunning et al (2010) and Waight and Oldrieve (2015) have demonstrated wide variation in the way that language and other features were used in adapted ER websites. Waight and Oldrieve (2015) also observed a tendency within production practice to ask co-producers with IDs to 'approve or disapprove' a web feature rather than to 'actively participate' (2015:7). Although they did

not elucidate on the meaning of 'active participation', they implied that the choices made through collaboration were likely based on preference rather than on performance.

In summary some evidence has pointed to the fact that ER literature within the public domain might be expected to vary in style, content and presentation and user groups often have clear preferences for how they like it to look. To date there has been no research that provides an overview of ER characteristics in a selection of documents published by one key producer.

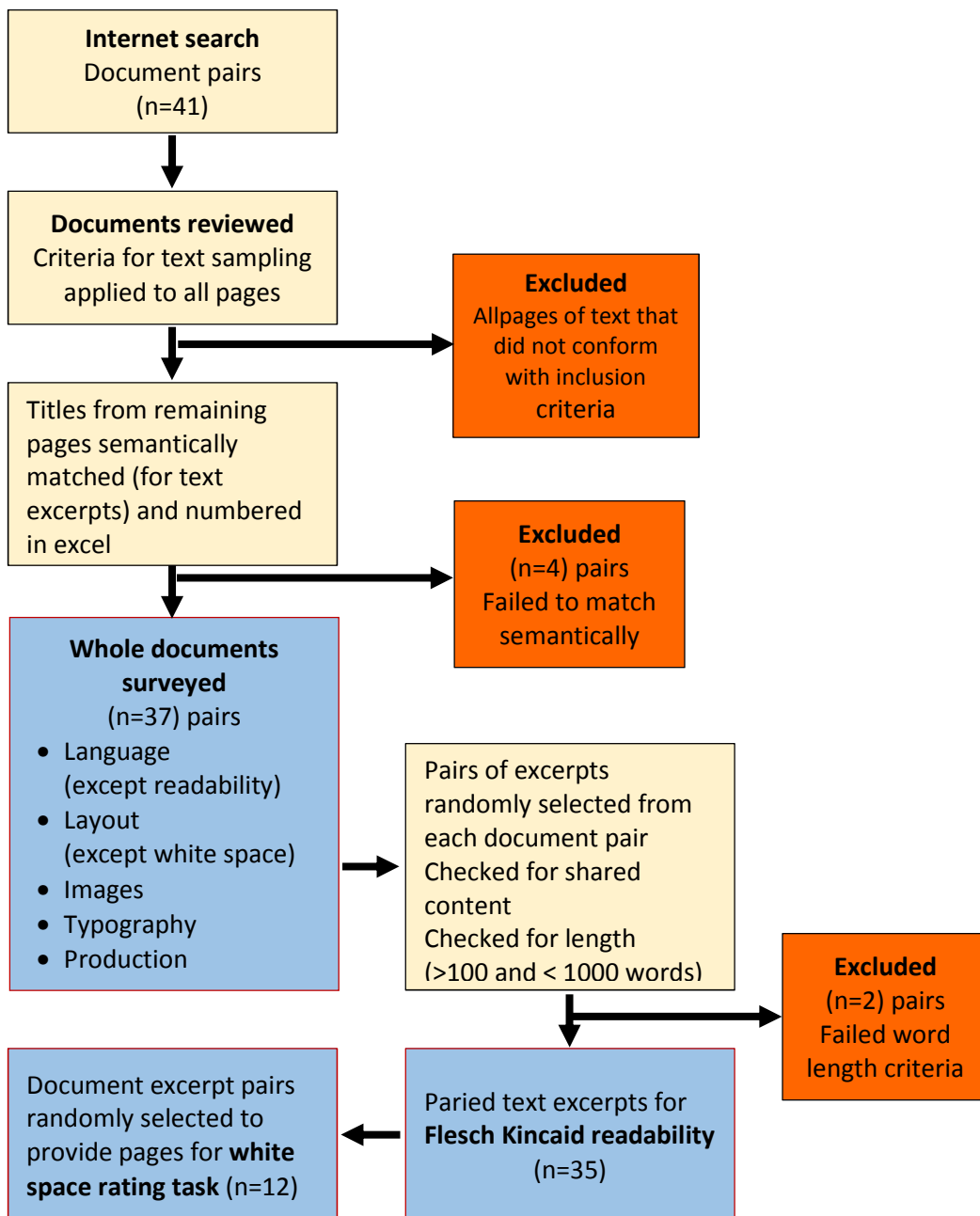
2.2 Study A: Aims and research questions

The central aim of the series of studies in The Easy Read Project concerned the contribution of ER material to the construction of meaningful information. As part of the route to achieving this, an examination of how it differed in presentation from N-ER material in terms of characteristics and variability helped to define the nature of the health related material on offer. Both groups of documents were sampled from the DoH website. The two-fold aim of the study was to: firstly, investigate the application of guideline features (DoH (2010), MENCAP (2002), Inclusion Europe (n.d.)) to a body of ER literature, and secondly, to compare these with features used in the equivalent N-ER documents. The main research question was: How does ER material compare to its N-ER comparators with reference to established categories in national and European guidelines?

2.3 Survey method

A descriptive, document-based survey of ER and N-ER documents published by the DoH was carried out. The process of identifying documents and the application of inclusion and exclusion criteria at different stages is shown in Figure 2.3.1 below.

Figure 2.3.1 Consort diagram for document selection and text sampling



Sample

The initial sample comprised forty-one ER documents and their N-ER counterparts published over a 12 year period (2000-2012) and available via the UK DoH website which was still active. A full list of the titles of the ER DoH documents included in the study can be found in Appendix Chapter 2. i The Survey, DoH Documents. Five documents were

about a health related experience, for example, a doctor's appointment. Eight were related to general health and wellbeing, for example, staying warm in winter and twenty three documents informed the reader about changes in policy that might affect them directly, for example, personal payment plans. The remaining five documents covered more abstract information, for example, the deprivation of liberty safeguards, research initiatives and human rights.

Documents were initially identified online through use of search terms: 'DoH easy read', 'easy read versions' 'Valuing People', then through a 'matching' option on the DoH search engine using 'easy read documents previously accessed', and finally by searching within the DoH website for publications month by month throughout the twelve year period. Any material produced by the DoH or the COI (Central Office for Information), labelled as 'easy read', 'with pictures', 'for learning disabilities', 'accessible', 'easy access', 'easy to read', or 'easier to read' was selected and included providing the title matched with a corresponding N-ER version. Each document pair was labelled with a name and a code and logged on an excel spread-sheet with its date of publication. A list of codes and document names can be found in Appendix Chapter 2. i The Survey, DoH Documents. These codes were used throughout this thesis apart from Study C: Discourse Features, where a small number of new codes were used and cross referenced to Appendix Chapter 2. i. Following the application of exclusion criteria as described below, thirty-seven document pairs were finally included in the survey.

Survey procedure

There were a number of exclusions that governed which parts of the documents were to be surveyed. Any pages containing text that precluded the normal use of morphosyntactic structures were excluded: cover pages, contents pages, appendices, glossaries and checklists, and full pages of quotes or speech bubbles. Pages that were associated with, but not directly related to the main content were also excluded i.e. prefaces and frequently asked questions, as were any pages that related to the administration or use of

the document e.g. 'how to use' sections. All remaining sections of text were included within the document survey.

Once the exclusions for text had been applied, sections of continuous text were matched by systematically comparing title headings. For the purposes of inclusion, title headings were defined as any word or complete statement used to indicate that the content of the subsequent text was set apart in grammar and in layout from the main content. Content matching between ER and N-ER texts by comparing titles ensured that superficially, the documents demonstrated reliable attempts to address the same information. Documents that did not demonstrate matching content at this stage were excluded as follows.

All titles within the forty-one pairs of documents were copied into an excel spreadsheet with ER and N-ER titles side by side in the order they were downloaded from the internet. Title headings were systematically compared based first on the use of the same words, then on the basis of semantically similar terms (synonyms) and then on the basis of semantically related words. For example ER title 'Part 2 - Information for patients, people who use services, carers and everyone else' (42E) was matched with N-ER title (42N) 'Chapter 2 – Information for patients, service users, carers and the public' (An Information Revolution DoH 2010). The title 'Justice' in the ER version (33E) of Valuing People Now: The New Strategy (DoH 2009) was matched with 'Access to justice and redress' in the N-ER version (33N). Further examples of matched title headings can be seen in Appendix Chapter 2. ii The Survey, Matched headings, as well as an example of non-matching titles (Appendix Chapter 2. iii) that led to document exclusion. In total, four pairs of documents were excluded at this stage leaving thirty-seven. Matching titles were identified in the excel spread-sheet through use of colour and were given corresponding numbers for ease of retrieval in preparation for sampling text excerpts for the readability analysis.

Final survey measures are shown in Table 2.3.1. These were drawn from the main categories identified in the review of guidelines (language, picture orientation, layout, image use, typography and production) in Table 2.1.1. Observed features under each category in Table 2.3.1 were identified to allow for as wide a capture as possible of the differences between ER and N-ER material. These were the simplification of language, layout, image use, typography and production.

All documents were printed in colour if colour was visible in the online version and were surveyed in paper A4 format. Each category was addressed separately and applied to every ER and N-ER document in turn. Tables and checklists were constructed on paper to provide a tally for each measure (except those for 'Readability' in the Language category and the 'White space' measure in the Layout category). These two exceptions are explained further in separate sections below. Calculations from tally sheets were transferred to an excel spreadsheet.

Descriptive statistics were used to summarise the results in each category. Where possible, the mean outcome measures for ER and N-ER groups was provided for comparison. Where this was not possible, the number of documents that displayed a particular feature was given out of the total number of thirty-seven documents. This was also represented as a percentage of the total.

Paired sample t-tests were then conducted to compare readability scores and main heading counts across ER and N-ER groups. Data for pages of text were not normally distributed. These data were included in the analysis process for the rest of the survey data which due to its nature was non-normally distributed. To check for significant differences between these survey features in ER and N-ER documents, SPSS Version 22 (IBM 2013) was used to conduct chi-squared tests, and where data did not fulfil requirements for this, Fisher's exact test was used.

Category measures

Each of the subcategories within the five main categories identified in Table 2.3.1 below, had its own methodology tailored to the nature of its itemised features.

Table 2.3.1 Survey measures

Category	Sub category	Feature	Measure
1. Language	Readability	Flesch Kincaid	Grade Score (<i>M</i>) (N = 35)
	Headings	Headings Subheadings Sub-sub headings Sub-sub-sub headings +	Number used in ER and N-ER (<i>M</i>) (N = 35)
2. Layout	Text	Use of text columns Use of graphs, figures and tables	Number and % of documents with feature out of total 37
	Image orientation	Images on right of page Images on left of page Images mixed left/right and/or interspersed throughout text Images aligned to text Images not specifically aligned to text	
	Image alignment	Images not specifically aligned to text	
	White space	More white space	
3. Images	Drawn images	DoH (source not specified) Contracted Illustrator 7 Access First Pack 'Say it works' pictures Change Picture Bank Valuing People Clip Art MENCAP	Number and % of documents with feature out of total 37
	Photographs	Source not specified	
	Drawn/photographs	Photo-symbols	
	Colour	Colour used in images	
4. Typography	Font point size	12 or less /14 /16 or more	Number and % of documents with feature out of total 37
	Font style	Arial Century Gothic/ MENCAP Times New Roman /Other Use of italics for emphasis	
	Font colour	Colour used in text	
5. Production	Length	Length of document (pages of text)	Mean number of text pages in 37 ER and N-ER documents
	Other support	Non-picture, mediating support advised	Number and % of documents demonstrating feature out of total 37
	Text support	'Difficult' words highlighted	
	Audio	Dvd or audio available	
	External publication	Publisher external to DoH	
Co-production	Consultation with target audience stated		

The process for measuring each feature and the rationale for its inclusion in the survey is specified in detail under each of the five categories..

1. Language

This category focused on the differences in language between ER and N-ER documents. The measure utilised two methods: automated readability scores, and a manual count of the total number of headings, sub-headings and sub-sub-headings in each of the document pairs. Means were calculated for both groups.

Readability measures

Further document preparation was necessary prior to running the automated measure for readability. Text excerpts from each document pair were sampled as follows and checked for content similarity and word length.

Shared content was checked by use of the matched and numbered title headings previously prepared in an excel spreadsheet. One pair of numbered text excerpts was selected from each document pair using an online randomiser (Research Randomizer). Selected excerpt pairs were compared within each document to ensure that both aimed to convey the same information. If the information was judged not similar, the next pair of numbered text excerpts in the document was chosen and checked manually for content similarity. This continued until two excerpts were found from each document that were judged to represent the same information.

The number of words in each text excerpt varied naturally. However, any sampled text that exceeded one thousand words or had less than one hundred words was excluded. The software Coh-Metrix (McNamara et al., 2014) used for readability measures in this study recommended that for the most robust outcomes, excerpts of text should be two hundred words in length. Due to the fact that simplification in ER material often covered

topics in less than two hundred words, a compromise of a minimum of one hundred words was established. Even the inclusion of one or two N-ER text excerpts that varied extensively in length from their ER versions could skew the mean comparisons such that it would not reflect the overall trend. Thus a ceiling level of one thousand words provided representative longer excerpts of N-ER text for comparison while reducing the risk of skewing outcomes by including the occasional excerpts of much longer text. Pairs of text excerpts that did not meet inclusion criteria for word length were discarded and the next numbered pair in the document was considered. If no numbered pairs of excerpts from a document pair fulfilled the established inclusion criteria for text length, the document was excluded from the sample. Following this process of checking the length of text excerpts, a further two document pairs were excluded leaving thirty five text pairs for preparation prior to running the readability analysis (See Appendix Chapter 2. i The Survey, DoH Documents).

In order to prepare texts for automated analysis, all thirty-five text excerpts were copied and pasted into a Word document and 'cleaned' as suggested by Coh-Metrix authors (McNamara et al., 2014). This process involved removing bullet points and any numbering outside the text, extra line spacing, indentations to text, columns and inverted commas. Title headings were not included in the text excerpts. All other punctuation was retained. The 'cleaning' process ensured that all documents were considered systematically and that the same automated rules were applied to each text. It avoided computational interpretation of such conventions as bullet points and inverted commas that could be erroneous.

The thirty-five cleaned and paired samples were then processed using the linguistic analysis software Coh-Metrix (McNamara et al., 2014) and measures for Flesch Kincaid Readability Grade Scores were extracted. A paired samples t-test was then carried out on these readability measures to check for differences between ER and N-ER material.

McNamara and Graesser (2010) have shown that when more letters and syllables were used in words, they were likely to be those less frequently found in common language. Furthermore, when sentences contained a higher number of words, it followed that it was probably more syntactically complex. They demonstrated that these two elements accounted for an increase in level of text difficulty. While limitations of traditional readability measures (Section 1.5.5 p.41) are acknowledged, the Flesch Kincaid Grade Score was used here to provide surface level information on specific aspects of difficulty and to provide a commonly recognised benchmark across all of the documents in both groups.

Heading counts

To gauge the levels of information presented in the different document groups, ER and N-ER, a count was made of all the title headings, sub-headings, and sub-sub headings in each of the original sample of thirty-seven document pairs. Title headings as defined under Survey Procedure were counted manually, and totals for each document were recorded in the excel spread-sheet. The mean number of headings, sub-headings, sub-sub-headings and sub-sub-sub headings plus any further layers were then calculated for ER and N-ER document types. Means of heading groups for ER and N-ER material were then compared for significance using SPSS to run paired samples t-tests

With reference to conventions such as headings and subheadings Keyes (1993) and Wright (1999a) have concluded that they provide an organisational steer to the reader and an indication of the depth of text content. Keyes (1993) demonstrated that a document with increasing layers of headings was found to be more complex and detailed than those without.

2. Layout

Layout referred to the way text, images and space were configured in document pages. The specific features measured were the organisation of text into columns, whether

graphs or other figures and tables were included and where images were placed in relation to the text. A further measure addressed whether the images were obviously aligned to the text. A checklist was used to note every incident in each document of text presented in columns, the presence of graphs, figures and tables, and images to the left or to the right of the page, interspersed images with text or mixed presentation. The tallies were transferred to the excel spreadsheet and totals and percentages were calculated. SPSS was used to process the data using a chi-squared test or Fisher's exact test to measure significant differences between these features in ER and N-ER texts.

Finally, a small scale human-rating experiment was carried out to test whether more or less white space was used in the ER documents compared to the N-ER documents. This process is described in detail below.

Both Keyes (1993) and Wright (1999a) have demonstrated that the layout of documents in material produced for the public played a part in how paper information was *processed* and understood (Section 1.5.4, p. 38). Williams & Hennig (2015) showed that processing at this level differed in different groups. They demonstrated that adults with IDs processed text and pictures sequentially rather than globally when retrieving information from websites. They concluded that images were therefore processed and interpreted linearly as if they were part of the text, rather than being processed strategically in relation to key titles, words or other pictures on the page. The evidence for sequential processing suggests that the use of columns to present text, and whether images are located to the left or the right of relevant text could present challenges to readers that single column texts or a sequential placement of pictures might minimise.

Structural devices such as bullet points, figures, graphs and spacing have been demonstrated to affect processing and are positively encouraged in the summarised ER guidelines (see Table 2.1.1). Wolgater & Shaver (2001) have demonstrated how the presence of bullet points increased information search time for participants who did not

have IDs, but they did not have an effect on the recall of information. Whilst this particular feature merits a fuller investigation into its influence on syntactic constructions and sentence length in ER information, it is beyond the scope of the current Study A. Figures, graphs and tables however, were considered. Wright (1999b) comments that they require a sophisticated understanding of text structure to make sense of the information presented due to the high demand on integrating images and text features. A document containing many figures and graphs could arguably prove more challenging to readers than one without.

White space measures

A participant rating of the amount of white space in ER compared to N-ER documents was undertaken to test the hypothesis that ER material contains more white space than its comparator.

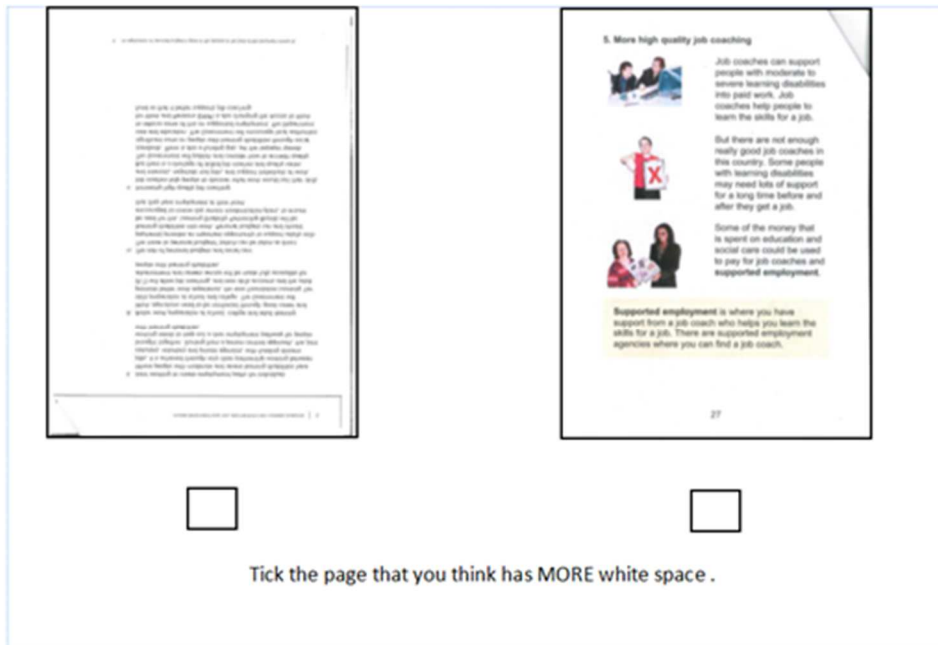
Using Research Randomizer online, twelve (one third) of the thirty-five document pairs used in the readability analysis were randomly selected. Previously identified matched and numbered headings were then used to randomly select, one pair of pages containing similar content from all twelve pairs (also using Research Randomizer)

These twelve pairs were used to compile a booklet where the ER pages and their N-ER comparator were displayed side by side as seen in Figure 2.3.2. Booklet. Participants were required to make a 'more or less' judgement about the comparative amount of white space present by ticking one of the boxes provided.

Forty seven participants were approached personally and recruited verbally on a one to one basis within the administration, teaching and research staff of the School of Health Sciences at the University of East Anglia. A brief explanation of the task was provided but participants were not told that half of the document pages were taken from ER material

nor were they told what ER material was. A completed and returned booklet was construed as consent for use of the data collected.

Figure 2.3.2 White space booklet



Nine participants were male and thirty eight were female, reflecting the female dominated pool of participants in the School of Health Sciences where recruitment took place. Participant ages ranged as follows: 16-21 (n=17); 22-30 (n=9); 31-40 (n=6); and 41+ (n=15). The completed booklets were reviewed and the group's ratings were collated. Raw scores for choices made (more white space in ER or N-ER examples) were expressed as percentages of the total number of possible decisions (564) for comparison. The difference between the number of ratings for more white space in ER versus N-ER was measured with SPSS using a chi-squared test.

Measurement for the use of white space has been shown to affect visual processing of information. Wright (1980; 1999b) has shown that manipulation of the white space around text, images and in margins has made a difference to how easy or ambiguous a text can be to eye-track for reading. The MENCAP (2002), DoH (2010) and European

Guidelines (n.d) for creating ER material direct producers to use more white space in their documents.

3. Images

This category tracked the use of drawn images, photographs, images that were a combination of drawn material and photographs in colour and in black and white. The presence of these distinct images was measured through systematic visual scanning and manual checking of each of the thirty-seven document pairs. Each document was surveyed page by page and the dominant type of image present was noted. Often credit was given to the copyrighted source of the images at the beginning or end of a document and if evident, this was also noted in an excel spread-sheet. Totals and percentages of the total number of documents displaying each image type were calculated. Differences were compared using SPSS. None of the comparisons fulfilled the criteria for a chi-square in this category, therefore Fisher's exact test was used to report on significance.

Different research groups and authors investigating images in ER material have demonstrated a variety of preferences. Participants in Owens (2006) study expressed a preference for photographs. Poncelas & Murphy (2006) used symbols, Williams & Hennig (2015) used a mixture of photos and symbols and Hurtado et al (2014) showed examples of the photographs used. As previously mentioned Keyes (1993) has demonstrated that colour in documents leads the eye, and readers (without IDs) grouped items of similar colour regardless of their meaning. Moreover, colour choice influenced interpretation and contributed to visual overload.

4. Typography

This category measured size, font and colour of the typescript used in each of the thirty-seven document pairs. A count was carried out manually. Again, every page of each document was scanned visually and font size was matched against a printed template of font sizes and styles previously created for this purpose. The template showed all the

fonts used in the document groups: Arial, Times New Roman, Century Gothic and Euphemia in font sizes ten to sixteen. Judgement could then be made about which category of font size had been used in each document: twelve or less, fourteen or sixteen and greater. The use of italics for emphasis was also noted and recorded in the Survey excel spreadsheet. The total number of documents using each font type and size was calculated, as well as percentages out of the total for each score and, differences were compared using SPSS. Where comparisons did not fulfil the criteria for a chi-squared test, Fisher's exact test was used to report on significance.

In terms of font, Silver and Braun (1993) have concluded that larger san serif style fonts are agreed to be the most easily read and this preference has been consistently backed up in focus groups (Owens 2006) and co-production groups who have created ER material (Rogers & Namaganda 2005; Ward & Townsley 2005; Tarleton 2005).

5. Production

The category of production included a measure of document length, whether non-picture or non-text support was advised or available (e.g. dvd, audio, human), and whether text support was provided in terms of highlighting or explaining words. Pages of text were counted for each document (taking into account exclusions previously described) and totals were noted in an excel spread-sheet. The mean number of text pages found in ER and N-ER text groups was calculated and the range established. Given that published guidelines (See Table 2.1 1) have recommended that information be provided in alternative formats for maximum accessibility, including DVD or audio format, a search was made for adherence to this in each document page by page. Other supporting textual features present in each document were identified in the form of additional cues characterising 'difficult' words or in advice to the reader to seek help to understand the information. Finally, the publisher of each document was identified where possible to establish if provenance was with the DoH or an external company and whether co-production had been acknowledged. As above, the number of documents with evidence of these features was logged in the excel spreadsheet. Totals and percentages of the

document groups displaying each feature were then calculated. Differences were compared using SPSS. Where comparisons did not fulfil the criteria for a chi-square test, Fisher's exact test was used to report on significance.

In the current study it was predicted that ER material would generally be shorter and contain fewer pages than the N-ER versions. This aligns with the process of simplification reflected by readability measures that aims to shorten words and phrases. Perception of length by the reader is influenced by the amount of text present and by the number of pages over which it is distributed. It appears that size of document as indicated by number of pages of text may contribute to reader motivation. Morgan and Moni (2008) found this subsequently affected how far a reader persevered with the text in terms of both reading and understanding. Perception of document length was a factor contributing to reader motivation and a measure of document length in terms of pages was therefore included as part of the survey.

Results were collated and are presented in a series of tables, each relating to the same categories described above: 1. Language, 2. Layout, 3. Images, 4. Typography and 5. Production. Paired t-tests were used to compare data that presented means (readability, headings and pages of text). As other data was nominal, chi-squared analysis was employed. Where more than 20% of the expected values were less than 5, the assumptions of chi-squared were violated and the Fisher's exact test was used. Where Fisher's exact test has been used, this is reported as the p -value only.

2.4 Survey results

Results for language measures are shown in Table 2.4.1. A paired samples t-test comparison of mean readability measures (Flesch-Kincaid Grade score) showed a significant difference in surface level complexity of language between ER texts ($M = 8.10$, $SD = 2.18$) and N-ER texts ($M = 13.4$, $SD = 3.7$), ($t(34) = -9.80$, $p = .001$). Standard

deviations indicated considerable variation in readability scores within each set of documents. These ranged from Grade 4 to 14 in the simplified excerpts and from Grade 5 to 26 in the N-ER versions. This indicates that some ER information used sentences and words that were as long as those used in N-ER texts.

Table.2.4.1 Language: means for readability and heading counts for ER and N-ER texts and associated comparisons using t-test analysis and Fisher’s exact test.

Subcategory	Feature	ER <i>M(SD)</i>	N-ER <i>M(SD)</i>	<i>p</i>
Readability	Flesch Kincaid (Grade Score)***	8 (6)	13 (5)	.001
Main	Main headings	10 (5)	10 (4)	NS
Headings	Total**	6(8)	32 (28)	.01
Subheadings ^a	Subheadings (One level)**	5 (7)	18 (17)	.009
	Sub-sub headings (Two level)**	1 (2)	9 (16)	.002
	Sub-sub-sub headings (Three level)**	0 (0)	4 (12)	.005

*** $p < .001$, ** $p < .01$, * $p < .05$. NS= not significant. ^aFisher’s exact test used

The mean number of main title headings calculated was similar in both document types but a greater numerical difference was revealed between the groups on use of subheadings. Levene’s test showed no significant difference between the groups on the data collected for main headings, ($t(72) = .075, p = .940$). A paired t-test comparison was then used to compare the number of main headings scores. Results showed no significant difference between the ER documents and N-ER documents ($M = 10.05, SD = 4.91$ and $M = 9.97, SD = 4.38$) respectively, ($t(36) = .085, p = .933$).

Overall, sub-headings did show significant differences between the two groups using Fisher’s exact test ($p = .01$) with more subheadings used in the N-ER versions than in the ER documents. Similar significant differences were found at all levels when broken down to compare subheading use between the two document groups at first ($p = .009$), second ($p = .002$) and third ($p = .005$) levels. This demonstrated that attempts were perhaps made to maintain the core information across both ER and N-ER versions. The ER documents used comparatively fewer sub-headings, even fewer sub-sub-headings and no ER

documents used more than three levels of headings. Eight N-ER documents did use sub-headings beyond three levels.

Table.2.4.2 Layout: use of columns, figures, images and white space in ER and N-ER texts and associated comparisons using chi-squared or Fisher’s exact test analysis

Subcategory	Feature	ER Total/37 (%)	N-ER Total/37 (%)	<i>p</i>
Text	Use of text columns*	1 (3)	7(19)	.03
	Use of graphs, figures and tables	11 (30)	16(43)	NS
Images orientation	Images on right of page**	8 (22)	(0)	.003
	Images on left of page***	19 (51)	(0)	.001
alignment	Images mixed left/right and/or interspersed throughout text**	10(27)	1(3)	.003
	Images aligned to text***	37(100)	2(6)	.001
White space	More white space Total /564 (%)***	537(95)	27(5)	.001

*** $p < .001$, ** $p < .01$, * $p < .05$. NS= not significant .

As shown in Table 2.4.2, a number of differences were revealed between the two text groups (ER and N-ER) regarding the layout of text and images. Of these features, the use of columns demonstrated a statistically significant difference between the groups when scores were compared using Fisher’s exact test ($p = .03$).

Chi-squared testing revealed no significant difference between the document groups on their use of graphs, figures and tables ($\chi^2(1) = 1.45, p > .05$). All of the other features were significantly more evident in the N-ER documents than in the ER group.

More than half of the ER texts maintained images on the left of the text. Twenty two percent however, placed images to the right of the text and a few distributed images around the text. N-ER versions differed in that none of them aligned pictures in this way with text. Statistical testing revealed that the these features were significantly more in evidence in the ER versions compared to the N-ER versions: images placed on the right ($p = .003$), images placed on the left, ($\chi^2 (1) = 25.56, p > .001$), images interspersed

throughout the text ($\chi^2(1) = 8.65, p = .003$) and images aligned to the text ($\chi^2(1) = 66.4, p < .001$). The high percentage (95%) of participant ratings in this survey showed that more white space was perceived to be consistently used in the ER versions as compared to the N-ER documents and this was confirmed when data were compared using chi-squared ($\chi^2(1) = 922.34, p < .001$).

Table.2.4.3 Images: source, type and colour in ER and N-ER texts and associated comparisons using chi-squared or Fisher's exact test analysis

Subcategory	Feature	ER Total /37 (%)	N-ER Total/3 7(%)	<i>p</i>
Drawn images	DoH (source not specified)***	13(35)	2(3)	.001
	Contracted Illustrator	2(6)	(0)	NS
	Access First Pack	1(3)	(0)	NS
	'Say it works' pictures	1(3)	(0)	NS
	Change Picture Bank	4(11)	1(3)	NS
	Valuing People Clip Art**	8(22)	(0)	.003
	MENCAP	1(3)	(0)	NS
Photographs	Source not specified*	7(19)	1(4)	.03
Drawn/photos	Photo-symbols***	13(35)	(0)	.001
Colour	Colour used in images***	36(97)	4(11)	.001

*** $p < .001$, ** $p < .01$, * $p < .05$. NS= not significant.

Images were used in every ER version and the range of sources can be seen in Table 2.4.3. These were manifest in ER as black and white line drawings, coloured drawings, symbols, photographs, cartoons or a combined version of two or more forms. Only a small proportion of the N-ER versions used images. As noted in findings related to language and layout, there was variability within the ER material regarding the type of pictures and images chosen. Nine different sources for images were cited in ER documents. The use of coloured images was evident in all except one ER document and in all four N-ER versions where images were used.

DoH images were used significantly more often in ER documents ($\chi^2(1) = 10.19, p = .001$), as were those from Valuing People Clipart, ($p = .003$). No significant difference was found between groups on any of the other drawn images ($p > 0.05$). In relation to photographic

images, the ER documents used significantly more overall. They used photos without a specified source significantly more often ($p = .03$), and Photosymbols were also implemented significantly more frequently, ($\chi^2(1) = 15.77, p = .001$). ER documents also demonstrated a significantly higher use of colour in images compared to N-ER documents ($\chi^2(1) = 55.71, p < .001$).

As demonstrated in Table 2.4.4, consistent differences were found in font size between the two text types and to a lesser extent, differences were identified in font style. ER documents applied point 16 or greater in ninety seven percent of cases, while N-ER material used point 12 or less in ninety two percent of their documents. Font style Arial was used in eighty six percent of ER documents and eighty one percent of the N-ER versions.

Table.2.4.4 Typography: font size, style and colour in ER and N-ER texts and associated comparisons using chi-squared or Fisher’s exact test analysis

Subcategory	Feature	ER Total/37 (%)	N-ER Total/37 (%)	<i>p</i>
Font point size	Size 12 or less***	(0)	34(92)	.001
	Size 14	1(3)	(0)	NS
	Size 16 or more***	34(97)	(0)	.001
Font style	Arial	32(86)	30(81)	NS
	Century Gothic/ MENCAP font	3(8)	(0)	NS
	Times New Roman*	1(3)	3(8)	.013
	Other	1(3)	4(11)	NS
	Use of italics for emphasis*	(0)	6(16)	.013
Font colour	Colour used in text	29(76)	28(73)	NS

*** $p < .001$, ** $p < .01$, * $p < .05$. NS= not significant

ER documents were revealed to use font size 16 (or more) significantly more often than the N-ER versions, ($\chi^2(1) = 74, p < .001$). The N-ER versions were found to use font size 12 (or less) significantly more ($\chi^2(1) = 62.9, p = .001$) and also showed significantly more use of Times New Roman font ($p = .013$) and italics ($p = .013$) than the ER versions. No significant differences between the groups was revealed in the use of size 14 fonts ($p >$

0.05), Arial ($\chi^2(1) = .398, p > .005$), Gothic, or 'other' fonts, ($p > .05$) or the use of colour ($\chi^2(1) = .76, p > .005$).

Table 2.4.5 below shows numerical differences between ER and N-ER production features. In terms of the number of pages of text calculated per document, on average, N-ER documents contained more pages of text than the ER versions, although several document pairs did not follow this trend. There were examples of ER documents that had many more pages of text than their N-ER comparator. The ER versions revealed more variation than their N-ER comparators as reflected in the range of pages. Statistical testing with Fisher's Exact Test revealed no significant difference in the number of pages of text used across the two document types, ($p > .05$).

Table.2.4.5 Production: document length and other support in ER and N-ER texts and associated comparisons using chi-squared or Fisher's Exact Test analysis

Subcategory	Feature	ER	N-ER	<i>p</i>
		Range (sd)	Range (sd)	
Length	Length of document (pages of text)	7-52(10.5)	2-156 (38.1)	NS
		Total/37(%)	Total/37(%)	
Other support	Non-picture, mediating support advised**	7 (27)	0	.006
Text support	'Difficult' words highlighted***	11 (19)	0	.001
Audio	Dvd or audio available	3 (8)	0	NS
External publication	Publisher external to DoH***	17 (43)	0	.001
Co-production	Consultation with target audience stated	4 (11)	0	NS

*** $p < .001$, ** $p < .01$, * $p < .05$. NS= not significant

Other production features identified in the ER versions (out-sourcing, co-production, alternative support within and outside the text) were not consistently or widely applied and were not found in the N-ER versions. Indeed when tested, directives for both other support, ($p = .006$) and text support ($\chi^2(1) = 12.92, p < .001$) were shown to be present significantly more often in the ER versions when compared to the N-ER versions. Audio

support was not significantly different in either document type. There were also significantly more N-ER documents produced internally by the DoH ($\chi^2(1) = 22.1$, $p < .001$), compared to ER versions which were more often produced externally. No statistical difference was revealed for the measure of co-production.

2.5 Survey discussion

The two document groups (ER and N-ER) differed noticeably across the categories compared. Modified features and production trends identified in the ER documents were consistent with many of the suggestions given in established guidelines (MENCAP (2002), DoH (2010), Inclusion Europe (n.d.)) as outlined in Table 2.1.1. Contrasting evidence between the two document sets suggests that efforts have been made to fulfil the requirement for reasonable adjustment in the ER versions as laid out in The Health and Social Care Act (2012). As expected, the text and layout features that characterised the differences between ER and N-ER literature were the same as those identified in previous research studies (Owens 2006; Rogers and Namaganda 2005; Waight and Oldrieve 2015; Ward and Townsley 2005; Tarleton 2005) to typify ER information. Surface level language was simpler according to readability measures, coloured images were aligned to the text, larger font was consistently used and more white space was judged to be incorporated. However, the use of these features and the way documents were produced varied widely within the sample of ER documents in contrast to the more consistent trends found in the production of N-ER versions. The following discussion of findings will be structured around the framework of established categories; language, layout, images, typography and production.

1. Language

In terms of language, overall shorter sentences and shorter words were used in the ER versions although the texts scored a mean of Grade 8 (US) on traditional readability measures. This was still well above the average reading ability of people with IDs which

Moni and Jobling (2001) and Jones (2006) have estimated as around age six to eight (Grade 1 to 4). The use of shorter words and sentences complies with some parts of the identified guidelines and are simplification processes that improve surface level understanding in readers without IDs (McNamara, 2013). Whether reducing word and sentence length encourages a fuller understanding of the text for people with IDs remains questionable. Furthermore, aiming to achieve a certain 'Grade score' through the use of readability measures may detract from the goal of creating texts that people with IDs can understand.

The variation in readability scores found in ER texts in Study A supports previous work by Bunning et al. (2010) who showed that language used in websites designed for people with IDs was not consistently less complex than that used in a comparable non-modified website. The overlap in readability scores between ER and N-ER documents further raises questions about what level of simplification qualifies for an ER version. It must be noted that such measures can only discover superficial complexities, and a more in depth analysis of language is required to establish if ER material is linguistically less complex on an underlying level where linguistic features interact and where cohesion and coherence are affected. This is addressed later in Study B: Linguistic Analysis of ER and N-ER DoH Documents and in Study C: Discourse Analysis of ER and N-ER DoH material.

Heading use demonstrated some compliance with the ER guidelines specification (See Table 2.1.1) that they should be 'clear', that 'information should be ordered in an easy way' and that 'all information about the same topic should be grouped together'. However, whilst topical content appeared to be maintained across ER and N-ER documents, depth of content was apparently compromised. Fewer sub-headings and no layers of sub-sub-headings beyond two indicated a briefer more superficial treatment in the ER versions of most of the topics addressed. It can be concluded that complex information was usually reduced in terms of depth of content in the ER versions compared to the N-ER material. This supports conclusions made about readability measures from findings in this study and also reinforces comments made by Walmsley

(2010; 2013) and Grove (2014) regarding the difficulties of representing inherently complex concepts in a simplified format.

Other guideline advice related to vocabulary, syntax and cohesion (Table 2.1.1) was not measureable through the readability formula or heading count, such as using proper names instead of pronouns, using repetition rather than variety, giving examples, avoiding metaphors and using active rather than passive tense. Crossley and McNamara (2008) demonstrated that the impact of these constructs on understanding is related to deeper level processing. They concluded that deep level understanding demanded an approach to simplification that addressed cognition and linguistics more closely. The repeated use of certain linguistic structures that might reduce a Grade score (such as the repetition of referents) has been observed to render them ineffectual as cohesive mechanisms (Kintsch & van Dijk 1978). Indeed, Fajardo et al. (2014) actively shortened sentences in an ER text and found that it increased the number of sentences. This resulted in poorer participant performance on answers to inferential questions about the content.

The influence of linguistic changes has been largely overlooked in research into ER material. The results from this survey showed that the kind of simplified language used in ER documents was less complex than the N-ER versions. However, research with other target audiences (Allen 2009; Crossley et al., 2007; Linderholm et al., 2000) into modification that involves shortening sentences and words has demonstrated that it does not consistently result in a document that is easier to understand.

2. Layout

ER documents showed a range of layout styles with pictures on both left and right of the page and more white space. N-ER documents were more consistent in their use of images and did not align them to the text. Variability in image placement demonstrated in ER documents might be explained by a lack of clarity in the guidelines such that local author

interpretation is invited. For example, in Table 2.1.1 advice can be found stating that only one picture should represent one idea and that pictures should clearly represent text and be linked to the content. Authors are encouraged to make ample use of space in ER documents, both in and around text and within margins. Deliberate use of white space, the avoidance of text columns, limited graphs and figures and clear alignment of pictures with text should make the retrieval of information easier as found by both Keyes (1993) and Williams and Hennig (2015). However, there is still no clear evidence to demonstrate how far such adaptations to layout contribute to the understanding of information for readers with IDs. Furthermore, Keyes (1993) has shown consistently that visual overload can occur when too many highly coloured items presented in both text and image format demand simultaneous visual processing by a reader.

3. Images

Images were more often used in ER compared to N-ER text although their style and provenance was mixed. Evidence for image use does not consistently support their contribution to understanding. While guidelines such as those summarised universally promote the use of images for ER material, they vary in specifying detail. For example some advice warns against images that are too numerous or complex and others stipulate they should be relevant, consistently used and in colour. The Inclusion Europe guidelines (n.d.) recommend that pictures for children should be avoided when working with adults, and the DoH (2010) guidelines suggest that different readers might prefer photographic images over drawn pictures. The presence of pictures in ER information has made little impact on users' ability to retrieve information quickly (Williams & Hennig, 2015), or to understand it better (Hurtado et al., 2014; Poncelas and Murphy, 2007). Nevertheless, readers often state that they like images in ER documents and they have demonstrated individual preferences for one type over another (Rogers & Namaganda, 2005, Ward & Townsley, 2005, Owens, 2006, Williams & Hennig, 2015). The discrepancies evident between the clear user preference for images in ER information and their apparent inconsequential effect on the understanding of text reflects the heterogeneity of the target audience and perhaps explains the variability of image type and use found in this survey. In conclusion, the use of pictures and images in ER documents, their relationship

to the meaning conveyed in text and their contribution to the understanding of printed information is an area that requires continued investigation. Images might well play a part in the process of understanding the content of ER material. However, processing symbolic and picture information is a complex area that deserves particular attention and as such it falls outside the scope of the current thesis.

4. Typography

Larger font (+16) was consistently used in the ER survey documents compared to the N-ER versions that usually used size 12. While variable advice is given in different guidelines about the use of coloured text and backgrounds in different guidelines, there is agreement across the three sets of advice reviewed that larger font will facilitate readers who experience literacy challenges, particularly at the stage of decoding information. While this is consistent with research evidence provided by Keyes (1993) who showed that large font reduced the initial effort involved in decoding print, there is no evidence to suggest that it makes any difference to the construction of meaningful information leading to a fuller understanding of the text for people with IDs. Indeed, Williams and Hennig (2015) found that participants with IDs scanned and retrieved information more quickly from adapted web-sites when the font was smaller rather than larger, despite their strongly expressed preference for larger font.

5. Production

Overall, N-ER versions were longer than their ER comparators. However, this was not consistently found to be the case. Some ER versions contained many more pages than the N-ER versions and the reverse was also found. Discrepancies in text length between ER and N-ER versions showed that decisions were made about what was considered the 'important information' to be included in the ER versions. Author choice was probably involved when considering text length. Fajardo et al. (2014) and Tarleton (2005) showed that texts perceived to be long demotivated readers with IDs. Whether the number of

pages used or text density contributed more to the perception of document length however, was not evidenced.

Outsourcing of ER development work to external organisations was met by just under half of the ER material whilst the N-ER documents were entirely produced internally by the DoH. This could explain the increased variation in style and format within the ER versions compared to the N-ER texts. However, only eleven percent of the ER documents stated that consultation had taken place with the target audience and these were all with outsourced organisations. Failing to acknowledge the process of co-production in documents does not equate to omission although given the emphasis on the importance of user participation in ER guidelines and its reported benefits, (Jones et al., 2006; Owens, 2006) the low number of acknowledgements was surprising. Similarly, despite clear evidence that literacy mediation can improve the understanding of written information (Katims, 2000; Papen, 2009) as well as encouragement within guidelines to alert readers to this, only twenty-seven percent of the ER documents explicitly followed guidance to advise the reader that they might need mediating support. An even smaller number (nineteen percent) highlighted 'difficult' words in the text. Finally only eight percent of the ER documents offered alternative dvd or audio versions as advised within guidelines. As might be expected, none of the N-ER versions acknowledged user consultation or provided advice for accessing alternative formats or human support for help in understanding.

2.5.1 Limitations of Study A: The Survey

The survey aimed to evaluate the extent to which common guidelines for ER material were followed and how these contributed to differences between ER and N-ER material. Arguably, the body of literature sampled was limited to that produced by one government department. Documents published by charities and other organisations might show less variability in both subject matter and presentation. Due to the wide

range of detail provided in different published guidelines, practicalities led to the use of consensus to provide the basis for the survey categories from the three most commonly cited versions (See Table 2.1.1 Summary guidelines and Table 2.3.1 Survey Measures). Consequently, some relevant features could have been overlooked.

Furthermore, the survey examined presentation and linguistic content of paper based material. It did not include digital formats of ER. It is also possible that the exclusions applied (e.g. cover sheets, indexes, prefaces, instruction sheets) removed aspects of the ER and N-ER documents that could contribute to the construction of meaning. As discussed, the use of traditional readability measures provided a commonly understood estimate of text difficulty and demonstrated that less complex syntax was used in ER material compared to N-ER versions. However, only surface level information (word, sentence and syllable length) could be identified through this measure and it did not take account of other aspects of vocabulary, syntax or cohesion that could contribute to understanding.

Finally, while the human rating on more or less white space clearly demonstrated that ER material was perceived to contain *more* white space, the participants were drawn from a pool of university employees. Results may have been more representative of the target audience if the rating had been carried out by people with IDs. Indeed, involving co-researchers in the whole process of construction and running of the survey could have provided a different set of measures in terms of the language used, image placement, font size, the use of colour and production features.

2.5.2 Conclusions and implications of Study A: The Survey

Key presentational differences and some surface level content differences were revealed between the two groups of text (ER and N-ER) across the categories of language, layout,

images, text and production. This clearly demonstrated some adherence to the advice in published guidelines for ER documents although as expected, there was noticeably more variation within the ER documents across all categories than found in the N-ER versions. This lack of uniformity found in the presentation of DoH ER material raises the question of what elements (apart from pictures and large print) define it.

Notwithstanding, there continues to be a market for ER material and this is supported by user groups. Production is likely to increase due to recent directives laid out in the Accessible Information Standard (NHS England 2016). This has cost implications in terms of time and the financial resources involved in production and dissemination of both hard copies and internet ER versions. It is possible that ER material conveys some concepts in a way that people with IDs can understand more easily than their N-ER counterparts. Its presence also addresses inclusion and the fulfilment of reasonable adjustment to information. Once a document is designated as ER, the implication is that it is fit for purpose in terms of contributing to the construction of meaning for people with IDs. However, there is no evidence to demonstrate what combination of the features used in ER material (if any) helps to activate the understanding of information at a deeper level such that it might be relevant and meaningful to the user in developing knowledge, making informed decisions and increasing autonomy in health care.

2.5.3 From document features to linguistic content

Study A: The Survey of DoH Documents has provided an overview of one grouping of ER literature and has outlined how it differed in key aspects of language and presentation from corresponding N-ER material. The range of differences evident in ER guidelines precluded a detailed investigation of every piece of advice provided although variation within the language and presentation of ER documents was evident. One of the main areas identified for further investigation was how language was constructed in ER material compared to N-ER material. Unlike picture material, the use of language in ER

documents has not received research attention. Given that the written word plays a central role in the representation and construction of meaning from printed material, particularly in relation to the way cohesive devices are used, this has provided the focus for Study B: Linguistic Analysis of Easy Read and Non-Easy Read DoH documents. Chapter 3 outlines and discusses the study of linguistic features undertaken.

Chapter 3. Study B: Linguistic Analysis. Making health information ‘easier’ to understand: a comparison of the linguistic features of UK DoH 'Easy Read' documents and their ‘Non-Easy Read’ counterparts.

Following on from Study A: The Survey, Study B aimed to compare the linguistic content of ER documents and their N-ER counterparts through an automated computational analysis. A number of measures were included, ranging from those that addressed surface level attributes such as sentence and word length, to those that addressed deeper level linguistic features related to syntax and cohesion.

3.1 Background to Linguistic Analysis

The background to this study focuses mainly on a detailed description of the automated software used for linguistic analysis, and how it has been used to measure deep-level linguistic devices related to cohesion and coherence. It then explores how simplification of language such as that found in ER material might be predicted to affect levels of coherence such that they influence the construction of understanding from text.

Coh-Metrix

Coh-Metrix is an automated software system for linguistic analysis based on Kintsch’s (1988) Construction-Integration (CI) model of text comprehension. Graesser et al. (2011) were instrumental in devising this system. The software has been extensively used to compare texts in educational and second language learning settings (Crossley et al., 2012; Graesser et al., 2011; Crossley & McNamara 2011; McNamara et al. 2014) where the aim is to ‘better match the text to the reader’ (McNamara et al 2014: 137). It draws on the idea that readers gradually construct understanding out of a systematic processing of the meaning of words and concepts as they appear within a text. Coh-Metrix is a dynamic model and open to multiple influences. The system was built out of an acknowledged

need for an automated package that could robustly measure psycholinguistic features related to text cohesion and coherence as well as surface level features (such as traditional readability measures). Coherence refers to the overall sense created by an integrated text and is influenced by cohesive devices and other linguistic features within a text.

According to Graesser et al. (2011) automated linguistic analysis using Coh-Metrix covers five major areas that are known to underpin text difficulty and that have been shown to account for most of the variance of reading performance across educational levels. These are described below in the following order: word concreteness, syntactic simplicity, referential cohesion, causal cohesion and narrativity.

Word concreteness refers to the concrete properties of a word. Highly concrete words are often more easily visualised. Syntactic simplicity is a measure of the simplicity of grammatical structures used. Cohesion refers to the way that connections are made within a text between words and ideas. Links are built through using referents (defined as 'the thing in the world that a word or phrase denotes or stands for' Oxford Dictionary) and this is known as referential cohesion. Common examples are 'he', 'it' or 'that one', or it might be the repetition of the word itself. For example, 'Councils must tell everyone about direct payments so that everyone who needs direct payments knows how to get them (Direct Payments Uptake Project, DoH 2006:6; 8E). In this sentence, both 'direct payments' and 'them' are referents for 'direct payments'. 'Everyone' has been repeated twice and therefore also functions as a referent through repetition. A referent may refer to an object, or it could be an imaginary or abstract thing. Causal cohesion is created through connections made with words such as 'because', 'whether', or 'despite'. Such features that aid linguistic cohesion in a text are often called cohesive devices. The final area is narrativity. According to McNamara et al. (2014), narrativity measures how close a text structure is to the kind of story construction that might be told in every day conversation. A text with high narrative measures would be expected to contain more familiar vocabulary, a clear beginning, middle and end and would be likely to address

topics that are within most people's knowledge of the world. Non-narrative texts are less familiar and usually contain vocabulary and concepts that are less commonly used. For example, a scientific text about the large hadron collider would be likely to contain less narrativity than a short fictional story. These five areas are broken down into smaller units within the Coh-Metrix system and are described in more detail in the Method section.

Benjamin (2012) recognised that the use of Coh-Metrix software avoided some of the issues of weak construct validity inherent in common readability measures. She argued that it provided an accurate linguistic analysis of large volumes of text and did not run the risk of inconsistency or error that might occur if done by human analysis. Furthermore, she pointed out that it eliminated issues with inter/ intra-rater reliability that could otherwise invalidate linguistic analysis. Apart from the benefits of being free to use, easy to implement and convenient due to its copy and paste facility as reported by Elfenbein (2011), Coh-Metrix has been shown to be a reliable and valid tool for analysing texts of up to fifteen thousand characters (roughly seven thousand five hundred words). Linguistic features in a number of large volumes of texts have been evaluated using this system. Crossley et al. (2007) examined one hundred and five texts used for teaching English as a second language, and also three hundred news texts (Crossley et al., 2012) for their levels of coherence. Louwse et al. (2004) has further used the software to compare differences in cohesion between written and spoken texts in twenty pieces of historical documentation.

McNamara et al (2010) have provided a comprehensive literature review of text-based studies that have contributed to validating Coh-Metrix as a reliable analytical tool. Texts which have been analysed by Coh-Metrix have also been incorporated into empirical investigations looking at which properties of simplified language interact to positively influence reading comprehension. Crossley et al. (2008) used the new psycholinguistic measures from Coh-Metrix to analyse data from two-hundred Japanese English language students. They showed that compared to traditional readability measures, Coh-Metrix

better reflected the cognitive mechanisms of reading, particularly for making sense of syntax and importantly for this study, in the construction of meaning through the use of cohesive devices.

Investigating the impact of linguistic coherence, McNamara et al. (2010) tested eighty university students to see if more or less knowledge of a topic made a difference to their understanding of high or low coherence texts aligned to Coh-Metrix measures. Findings showed that readers with higher levels of background knowledge learned more from texts that were less coherent, whereas low knowledge readers benefitted from high coherence text with increased cohesive cues. (Background knowledge was assessed through the administration of prior knowledge questions for each set of texts before participants undertook the experiment.) Crossley et al. (2014) further set up a study of forty-eight second language learners who read texts at three different levels of simplification. They concluded that simplifying educational texts did result in increased text comprehension but this positive effect was dependent on how well the students could read in the first place. Furthermore, consistent with McNamara et al. (2010), different levels of background knowledge students had about the reading topic influenced reading comprehension outcomes in Crossley et al.'s (2014) study in the same way. Participants with less knowledge gained more from the adapted text than those with better knowledge.

Research into the linguistic properties of texts has illustrated the complexities elicited from multi-level linguistic analyses. This is further complicated when texts are presented to readers in real life. The constituent parts of language used in texts and how they impact on understanding through reading are of an intricacy beyond that which is reasonably measured by a popular readability formula. As yet, no analyses of this kind have been found that specifically compare ER material with N-ER material or that attend to the linguistic outcomes of simplification processes in current examples of ER documents.

Cohesion and coherence

Cohesion is what helps the reader derive a deeper understanding of the causal events, processes and actions in texts. McNamara (2013) argued that if a text is made up of a number of relationships that are *not* explicitly linked, the reader is left to make those connections through inferential processing. In contrast, if the relationships are explicitly represented within the text in the form of cohesive links, the text is likely to be cohesive at a deeper level. She has further shown that linguistic and cognitive difficulties may compound problems with inferencing for some readers who may need more explicit linguistic cues to gain a coherent understanding of a text's central meaning. Henderson et al. (2013) has also reported that readers with poor background knowledge or limited experience of the topic find it more difficult to make inferences than those with direct experience of the reading topic.

The effect of simplification on cohesion and coherence

Allen (2009) and Benjamin (2012) have demonstrated how linguistic constructs affecting cohesion and coherence were often altered through processes of simplification. While the aim was to improve reader understanding, the effect of simplifying language did not always result in texts that were more coherent or easier to understand. Coherence is understood to be influenced by multiple linguistic and contextual factors and Allen (2009) showed that these were not always recognised as crucial to the construction of meaning when processes of simplification took place. He concluded that overall coherence impacted on the reader's ability to respond to the information in the text, to contextualise it within time and to situate it relation to their own life and experience.

There has been limited research on the relationship of cohesive devices to deep level understanding in ER documents. Fajardo et al. (2014) measured inferential and literal understanding of adapted texts and found that increased overlap of terms (co-reference) negatively affected reading comprehension. They also found that surface level changes (increasing word frequency and reducing word length) did not make any significant

difference to performance (Section 1.5.6, p. 46). This is in contrast to findings by Crossley et al. (2007; 2012) and McNamara et al. (2007; 2010), where increased cohesion achieved through more overlap of semantic terms was shown to positively affect reading comprehension in participants without IDs, as were surface level changes (shortening words and sentences), particularly for weaker readers. It is possible that authors adapting documents for the IDs target group might be using cohesive devices differently to those modifying text for other target groups. For example, the use of linguistic features used in ER documents, e.g. increased repetition of the same words rather than the use of semantically related words may have affected the potential benefits of cohesive devices to the reader with IDs in Fajardo's (2014) study. In contrast, McNamara (2014) looked at reading ability in readers *without* IDs and suggested that the effect of background knowledge on their understanding of texts was greater than the effect of reading proficiency. Another possibility is that there could have been qualitative differences in the way that different target audiences engaged with the texts in these two studies. As reported by Chinn (2014), people with IDs often have variable profiles of background knowledge related to individual experience, especially in relation to their own health.

The process of relating the information from text to life experience in the real world has been referred to in cognitive psychology by Kintsch & van Dijk (1978) as the 'situation model'. They proposed that readers build internal representations of what they are reading and these are shaped by their own personal experience, background knowledge and familiarity with the topic. McNamara (2013) described the complexity of devising a model to measure the interaction between the (extrinsic) multiple characteristics of a text and the (intrinsic) differences in individual readers. Rather than provide measures of single linguistic (intrinsic) features, Coh-Metrix has been described as achieving a measure of the multiple characteristics of text. It aligns itself to theories of discourse and reflects the idea that comprehension operates at multiple levels. The software controls for multiple variables within experiments thus achieving tighter regulation of measures and a more robust set of core data. (Elfenbein 2011; McNamara 2013).

In summary, Coh-Metrix software provides reliable multiple measures for large volumes of text. This allows for analysis of the interactions between a number of linguistic variables that underpin how cohesion and coherence are constructed within text. It has often been used to compare two groups of texts and is therefore suitable for a comparative linguistic analysis of the DoH documents previously sampled for Study A: The Survey. Linguistic cohesion and overall coherence have been shown to affect how well printed material is understood at a deeper level and how easily it can be linked to real life experience. Whether these structures are affected by the simplification processes commonly used in ER material is not yet established.

3.2 Study B: Aims and research questions

Study B. Linguistic Analysis aimed to establish critical differences between the linguistic features of DoH documents rendered as ER and those that were N-ER. It built on the findings of presentational and surface level linguistic features examined in Study A: The Survey, taking the analysis to a deeper level. The primary research question was: How do ER and N-ER DoH documents differ in terms of the linguistic features used in surface and deep level understanding of text? A subsidiary question was: What features dominate in the comparison of differences?

It was hypothesised that ER literature would be descriptively, syntactically, and inferentially less complex than its N-ER comparators because it would be tailored to a particular target audience. The use of shorter sentences and words was expected, with a greater number of high frequency, concrete vocabulary that was easily visualised. These features typified the ER material examined in Study A: The Survey and correspond with the common guideline advice summarised in Study A, Table 2.1.1. A lower variation of words and an increased incidence of the use of co-referents was also predicted as these can be a linguistic outcome of simplification (Allen 2009). Conversely, fewer connectives and simpler syntax were anticipated, as a result of shortened sentences. The amount of semantic coherence within the texts was more difficult to predict. As described in the

section on Background, coherence results from the interaction of a combination of linguistic features and can also be influenced by contexts external to the text such as personal experience of the subject matter. Nonetheless, it was anticipated that the analysis would demonstrate higher levels of coherence in the ER texts due to more frequent use of cohesive devices. This would indicate that the simplified versions were optimally adapted for the information to be linked to the readers' situation model (McNamara 2013) and for understanding to be more quickly and easily established.

3.3 Linguistic Analysis method

A comparative survey of linguistic components featuring in ER documents and their equivalent N-ER versions was conducted using computational metrics. These were analysed for comparison on selected measures as described below under Data analysis and outlined in Table 3.3.1. Coh-Metrix Measures.

Text sampling and preparation

The sample comprised the same thirty-five ER documents and their N-ER counterparts sampled previously from the pool of forty-one pairs identified on the DoH website using specific search terms (see Study A: Survey method p.85). The names of these documents are listed in Appendix Chapter 2. i The Survey, DoH documents. Exclusion criteria applied to pages of text, matching for titles and content of text excerpts and sampling for text excerpts were the same as those given in detail in Study A: Survey method p. 86. The remaining thirty-five pairs of sampled text were copied and pasted into Word documents and 'cleaned' as described on p.92. Again, this ensured that all documents were considered systematically and that the same automated rules were applied to each text, avoiding computation interpretation of conventional bullet points that could be erroneous. These were then processed using automated linguistic analysis.

Data processing and analysis

Data processing was carried out using the open source, automated software Coh-Metrix version 3.0 (Graesser et al., 2011). Coh-Metrix extracts a wide range of linguistic indices from text. It is made up of a number of known linguistic measures that are conventionally used for this purpose. Some of these measures rely on human ratings that have been carried out in large numbers and stored as publicly available databases. These include the MRC Psycholinguistic database (Coltheart, 1981), CELEX from the Netherlands (Dutch Centre for Lexical Information) and WordNet (Miller et al., 1990). Other measures have been devised by Coh-Metrix researchers using a complex system of algorithms based on linguistic theory to provide a score e.g. latent semantic analysis, measure of text and lexical diversity (MTLD), and comparisons such as the amount of 'given' (or repeated) information as opposed to 'new' in a text (McNamara et al. 2014).

In order to investigate the differences between linguistic features used in ER and N-ER documents, text samples were processed using sixteen indices from Coh-Metrix grouped within six areas of measurement. McNamara et al. (2014: 167) defined groups of indices that 'purport to measure the same linguistic construct' within Coh-Metrix as a 'measure'. The indices within a measure would be considered to be strongly related and would therefore be highly correlated. McNamara et al. (2014) recommended a conservative ratio of 20:1 when selecting measures against the number of document pieces under scrutiny with the proviso that the nature of the research question and the area of focus should be considered on a case to case basis. Six measures were finally selected for linguistic analysis of ER and N-ER material: word attributes, syntactic complexity, lexical diversity, connectives, referential cohesion and situation model (deep cohesion). These were measures that were either directly referred to in previous research pertaining to the simplification of ER documents (for example, Fajardo et al., (2014) investigated the role of connectives) or they addressed issues that were raised through current findings related to the influence of linguistic cohesion in reading comprehension. The category 'word attributes' provided qualitative ratings of words and was less closely related to the other five measures which were more interdependent in their contribution to the construction

of text cohesion. Care was taken to select a range of measures that covered features at word, phrase, sentence and text levels.

Aside from the central six measures identified, descriptive measures (the number of words and sentences used as well as word and syllable length) were also carried out. These served to expand on the general surface level information about the text excerpts previously provided by Flesch-Kincaid readability scores reported in Study A, The Survey. These measured features that corresponded to the current advice provided by guidelines for reducing word and sentences length in ER material, and that were summarised in Study A: Table 2.1.1 Summary of guidelines. The indices used and calculation methods for each (including descriptive measures which are listed first) are described in Table 3.3.1. Coh-Matrix Measures below. Each measure in turn is then explained in more detail.

Table 3.3.1 Coh-Matrix measures

Measure	Indices	Description of measure	Calculation/ process
Descriptive	Sentence count	sentences in text	Total
	Word count	words in text	Total
	Sentence length	words in sentences	mean number
	Word length	syllables in words	mean number
Word attributes	Word frequency	(CELEX Log) that uses a corpus of 17.9 million (spoken and written) words.	mean log (base of 10) for all word tokens in text (excluding those not included in CELEX database).
	Familiarity for content words	MRC Psycholinguistic database based on human ratings for 3488 words	mean rating: 1 (unfamiliar) to 7 (very familiar)
	Concreteness for content words	MRC Psycholinguistic database based on ratings for 4293 words	mean rating for each word: 100 (highly abstract) to 700 (highly concrete)
	Imageability for content words	MRC Psycholinguistic database based on ratings for 4825	mean rating for each word: highly difficult to represent as an image) – 700 (highly imageable)
	Polysemy (ambiguity) for content words	Relations measured in WordNet	Low value rating (eg. 1 = specific use; high vlue reflects less specific use.,
Syntactic complexity	Left embeddedness of verb in clause or sentence	Position of main verb	mean number of words before main verb in text

Table 3.3.1 Coh-Metrix Measures continued

Measure	Indices	Description of measure	Calculation/ process
Syntactic complexity continued	Sentence syntax similarity	Repeated syntactic structures	mean of all combinations of similar syntax measured across paragraphs
	Semantic overlap	Latent semantic Analysis (LSA)	0 = low cohesion to 1= high cohesion
	Semantic overlap	Latent semantic ratio (given/new information = G/N)	Algorithm resulting in ratio 0 = less given info (low cohesion) to 1 = more given info (high cohesion)
Connectives	All connecting words	Connecting words: causal 'because, so', logical 'and, or', adversative/contrastive 'although, whereas', temporal 'first, until' additive 'and, moreover', positive 'also' and negative 'however, but'	mean incidence (in 1000) of all connectives, mean number of connectives in text
Lexical diversity	Variation of words in text	New and repeated words in text	type-token ratio (TTR) measured by dividing each unique word (type) by the number of times it is repeated (token)
	Lexical Textual diversity	New and repeated words in text	algorithm-based TTR to account for differences in text lengths (MTLD)
Referential cohesion	Noun overlap	Repeated nouns	mean incidence (in 1000) between all sentences based on nouns, and noun phrases
	Argument overlap	Repeated nouns and pronouns	mean incidence (in 1000) between between all sentences based on nouns, pronouns and noun phrases.
	Stem overlap	Repetition of word 'roots' e.g. carer, caring, care.	mean incidence (in 1000) between all sentences based on similarity of the root of the word (lemma)
Situation model (deep cohesion)	Temporal cohesion	Tense and aspect repetition (van Dijk & Kintsch 1983)	mean incidence (in 1000) of representations of time indicated through verb tense.

As mentioned, mean word and sentence counts and mean word length (syllables) provided general descriptive information about the texts. These were expected to demonstrate findings in line with the pattern shown by Flesch Kincaid Readability scores

in Study A. They provided surface level measures of text difficulty. Fewer sentences and fewer words in total with shorter sentences containing shorter words were therefore anticipated in the ER documents compared to excerpts from the N-ER documents. Readability scores varied widely across both ER and N-ER documents and the overlap of scores across the two groups suggested the need for a further breakdown of this outcome. Fewer sentences overall could indicate more complex constructions or less content, while the number of words used demonstrated the overall length of text used to deliver the same information for comparison between ER and N-ER versions. Sentence length has been shown to predict reading time (Haberlandt & Graesser, 1985; Just & Carpenter, 1987; Rayner, 1990 cited in Graesser et. al., 2011) while increasing sentence length has been shown to require increased efficiency of working memory. Word length also predicted reading time in Graesser et al. (2011) where they showed that an increased word length required increased efficiency of phonological ability and again, placed more burden on working memory.

Word attributes measured content words in several categories: frequency, familiarity, concreteness, imageability and ambiguity. These have been given human ratings for their differing properties and are drawn from the MRC Psycholinguistic database (Coltheart 1981). Words that are more frequently used in everyday language are more easily recognised and processed by the reader. 'Familiar' words are those acquired early in development, and used more often in everyday life. As a result, they also tend to be easier to recognise in text and are therefore more quickly processed for reading. 'Concreteness' was used to measure how abstract words were. Lower ratings appeared if a large number of abstract concepts were present or if words lacked specificity. Concrete words are more easily cognitively represented and are easier to understand. 'Imageability' provided a rating for how easy it is to create a mental image of a word once it is recognised in text. Words that are highly 'imageable' are more easily processed and understood. This is linked to measures of familiarity and concreteness. Polysemy measured the average number of different meanings or senses that words in the text could have. Words that are more frequently used tend to have much higher levels of

polysemy (ambiguity). This could make a text more difficult to understand accurately despite having a high level of frequently used words.

Syntactic complexity in terms of the left embeddness of verbs and semantic overlap of terms was calculated. A high number of words counted before the main verb in a sentence indicated high grammatical complexity and thus could be predicted to require bigger working memory capacity to process successfully. Additionally, texts that were composed of a number of sentences that were similar in structure could be easier for the reader to process. A measure for syntactic similarity was also therefore included. Semantic Overlap entailed measures of Latent Semantic Analysis (LSA), which were calculated through the number of times semantically-related items could be tracked throughout a text thus contributing to levels of deep cohesion. In a similar way, 'New/Given' Latent Semantic Ratios were calculated by measuring the amount of semantically new information presented against the amount of information that has already been given (or previously referred to) by semantically related words or phrases. Texts that had high semantic latency were considered to be more cohesive and should be easier for the reader to make sense of.

Lexical diversity was measured by Type Token Ratio (TTR), a commonly used measure that demonstrates the variation of words used in a text. Texts with a high 'TTR' close to 1 indicated that each word was repeated only once in the text. This level of lexical diversity means that a text could be more difficult to understand because it contains a higher number of different words. TTRs that decrease in value from 1 indicated that the same words were repeated more often in a text. In theory, this would make the text easier and faster to process because there are fewer words to understand. Lexical textual diversity (MLTD) was a more complex measure of ratio. When texts differ in length, the ratio for comparison becomes less reliable. McCarthy and Jarvis (2010) therefore used a sophisticated set of algorithms to extend the measure from basic TTR to account for difference in text lengths within the MLTD measure. This was relevant to the current

study where texts under comparison varied in length, thus both TTR and MLTD measures were applied.

Referential cohesion, constructed through the use of cohesive devices provided the reader with reference to previously stated information, e.g. themes, actors, actions or events. The repetition of words or terms and the use of pronouns make connections between clauses and sentences. This helps the reader to follow the text and was measured in several ways. Noun overlap measured the number of nouns and noun phrase repetitions in each text. Similarly, stem overlap measured the level of noun, pronoun and noun phrase overlap between sentences. Argument overlap measured the number of repeated words between sentences based on the similarity of the word root (lemma), e.g. caring, care, carer, carers.

Deep cohesion was addressed through a more complex measure of the patterns of cohesive devices used. This was linked to the referential cohesion of the text and depended on how easy it would be for a reader to construct a mental representation while reading (situation model). The mental representation draws on personal experience and knowledge and is activated by words and ideas conveyed in the text. An estimate of how well text supported this was measured through calculating the incidence of temporal cohesion, the connectives used and the amount of semantic overlap between words and phrases. Texts that rely heavily on mental representation of the context presented will likely be more difficult for the reader to access for understanding, particularly if they rely on the mental representation of abstract concepts such as time, usually indicated through verb tense. Such a text might demand higher levels of abstract understanding about time, positive and negative inference and cause and effect. A text with sophisticated use of connectives reflected a higher emphasis on text organisation which could help skilled readers but might not necessarily be of use to less skilled readers in terms of understanding the content.

Mean scores from ER and N-ER text samples were calculated for each of the sixteen main indices and for the descriptive indices. Data were tested for normal distribution using the Shapiro-Wilks test. Where data were found to be normal, paired sample t-tests using SPSS Statistics Version 22 (IBM 2013) were conducted on indices scores. Where data proved non-parametric, Wilcoxon's signed-rank test was used as indicated in Table 3.4.1. Differences between ER and N-ER text groups were compared on each index and differences were considered across overall measures. Comparisons to Coh-Metrix norms on indices relating to educational texts suitable for levels of reading ability between ages 5 to 9 years (McNamara et al. 2014: 76) were used where this supported explanations of significance differences on specific indices. Very small changes in the mean score of an index have been shown to represent clear and significant differences in the use and presence of specific linguistic features between documents adjusted for beginning readers and those prepared for older more experienced readers.

3.4 Linguistic Analysis results

Results for the descriptive measures are explained below. The six main measures are then displayed in Table 3.4.1. where means and p -values are provided for both ER and N-ER Coh-Metrix outcomes on each of sixteen indices covering: word attributes, syntactic complexity, connectives, lexical diversity, referential cohesion and situation model (deep cohesion).

None of the data relating to descriptive indices were found to be normally distributed when tested using Shapiro Wilk's test for normality ($p < .05$). There was a higher mean total number of words in the N-ER documents ($M = 279, SD 205.57$) compared to the ER material ($M = 190.26, SD 109.53$) and Wilcoxon's signed-rank test for non-parametric data revealed this to be significant ($Z = -2.47, p = .014$). The mean number of words per sentence was also higher in N-ER material ($M = 24.43, SD = 6.33$), than in ER documents ($M = 17.97, SD = 3.80$) and this was confirmed as significantly different also using a Wilcoxon's signed rank test ($Z = 4.37, p < .001$). The mean number of syllables per word

was similarly revealed to be significantly higher in the N-ER excerpts ($M = 1.65, SD = 0.16$) than in the ER excerpts ($M = 1.41, SD = 0.11$), ($Z = -5.16, p < .001$). The mean number of sentences used was also slightly higher in the N-ER material ($M = 11.77, SD = 8.42$) than the mean number of sentences overall in the ER documents ($M = 11.14, SD = 7.79$) although this was not statistically significant ($Z = -.388, p = .698$).

Although the difference between means and standard deviations appears very small on the indice for word length (number of syllables in words), it is in line with the progression of text difficulty reflected in Coh-Metrix norms (McNamara et al., 2014). The mean number of syllables per words in very simple material (for 5 year olds) was reported by them as $M = 1.2$ ($SD = 1.6$) and means in much more complex material where longer words were used, increased marginally up to $M = 1.27$ ($SD = 0.05$) in texts for 7-8 year olds, and to $M = 1.32$ ($SD = 0.07$) for 9-10 year olds. The related nature of the descriptive indices meant that where statistical significance was revealed in one comparison, significant differences in comparison of other indices within the measure was also likely.

Table 3.4.1 Means for ER and N-ER Coh-Metrix main indices

Variable	ER		N-ER		Diff (CI 95%)	p
	M	SD	M	SD		
Word attributes (content words)						
Word frequency ***	3.10	0.21	2.94	0.11	0.16	.001
Familiarity***	583.13	9.17	566.46	10.03	16.67	.001
Concreteness*	375.32	0.26	366.74	20.42	8.60	.038
Imageability*	406.21	23.57	397.30	16.99	8.91	.033
Polysemy***	5.01	0.715	4.08	0.55	0.92	.001
Syntactic complexity						
Words before main verb ^a	3.62	1.48	3.87	1.83	0.25	.563
Syntax similarity; all sentences ^{a***}	0.11	0.03	0.07	0.02	0.04	.001
LSA: overlap in all sentences ^a	0.25	0.12	0.25	0.10	0.00	.993
Given/ New info ratio (LSA)*	0.34	0.05	0.30	0.06	0.03	.018
Connectives						
all types***	86.36	22.07	107.74	29.22	21.38	.001
Lexical diversity						
Type token ratio*	0.51	0.07	0.55	0.08	0.04	.025
Lexical textual diversity***	53.15	11.50	75.02	17.87	21.38	.001
Referential cohesion						
Argument overlap; all sentences*	0.71	0.18	0.62	0.18	0.09	.039
Noun overlap; all sentences	0.55	0.23	0.51	0.22	.036	.422
Stem overlap; all sentences	0.61	0.23	0.59	0.21	0.03	.526
Situation model (deep cohesion)						
Temporal cohesion; tense/aspect	0.83	0.13	0.77	0.12	0.06	.062

^a Wilcoxon's signed-rank test conducted

Significant linguistic differences between ER and N-ER documents ($p < 0.05$) were revealed in eleven out of the sixteen indices as shown in Table 3.4.1, although when seen grouped as clusters of closely related features broken down within six main measures, the profiles within each measure and their relative differences becomes of interest.

Word attributes revealed statistically significant differences between the groups on word frequency, familiarity, concreteness, imageability and polysemy measures, all of which were higher in the ER material compared to N-ER versions. Of these, differences in word frequency, familiarity and polysemy measures were strongly significant. This indicated that more common-place words which were more easily visualised were used significantly more often in the ER texts than in their N-ER counterparts. This group of significant measures was not unexpected due to the strong relationships between these linguistic indices.

Measures for word frequency in ER ($M = 3.10$, $SD = 0.21$) compared to N-ER ($M = 2.94$, $SD = 0.11$) using a Wilcoxon signed ranks test for non-parametric data showed a significant difference ($Z = -5.08$, $p < .001$). Although the difference between seemed minimal to be reliably significant, reference to Grade level norms (McNamara et al., 2014) for Coh-Metrix also revealed minimal differences between word frequency means in documents prepared for 5 - 6 year olds ($M = 3.14$, $SD = 0.11$) and those prepared for 7- 8 year olds ($M = 3.09$, $SD = 0.04$) on a steady trajectory of incremental scores up to those prepared for 13 year olds ($M = 3.05$, $SD = 0.09$). Comparison with these norms allows for a clearer interpretation of the significant difference found on the measure of word frequency in ER compared to N-ER documents.

Deeper level understanding, influenced by features related to syntactic complexity, the use of connectives, lexical diversity, and cohesion, resulted in more complex outcomes. Of eleven indices related to these features, three showed strongly significant differences between ER and N-ER document groups: syntactic similarity, lexical textual diversity (MLTD) and the use of connectives. These reflected a higher incidence of similar or repeated syntactic structures, and a much lower variability (MLTD) of vocabulary in ER documents compared to their N-ER counterparts. As with the measure of word frequency above, the difference between means on the indice measuring syntactic similarity also showed a significant difference between ER ($M = 0.11$, $SD = 0.3$) and N-ER ($M = 0.07$, $SD = 0.02$) but seemed minimal. However, mean syntactic similarity scores from Coh-Metrix

norms (McNamara et al., 2014) contextualised this significance. Scores from documents prepared for 5 and 6 year olds ($M = 0.17$, $SD = 0.06$) compared to those prepared for 7 – 8 year olds ($M = 0.14$, $SD = 0.04$) demonstrated small increments but represented a substantial difference in the texts' syntactic configuration, again increasing to texts prepared for 13 year olds ($M = 0.09$, $SD = 0.03$).

Significantly fewer connectives were used in ER material which also corresponds with the shorter sentence lengths used. These findings suggested that ER material was created with a comparatively limited range of vocabulary and that more words, phrases and grammatical structures were repeated than in the N-ER versions. As would be expected significant differences between document types were also found in both indices for G/N information and TTR due to their strong correlation with indices of syntactic similarity and MLTD respectively (McNamara et al. 2014).

Using Wilcoxon's signed ranks test for non-parametric data, there was no significant difference between the two text groups ER ($M = 0.25$, $SD = 0.12$) and N-ER ($M = 0.25$, $SD = 0.10$), ($Z = -.388$, $p = .825$) in the amount of semantic overlap (LSA) used in sentences suggesting that a similar number of semantically related terms were used within both document types. Nor was there any significant difference in the number of words that came before the main verb in sentences between ER ($M = 0.25$, $SD = 0.12$) and N-ER ($M = 0.25$, $SD = 0.10$) versions ($Z = -.426$, $p = .670$) also using Wilcoxon's signed ranks test.

In terms of referential cohesion, the significant difference in argument overlap suggests there was a higher number of co-referents (overlap) evident in the ER texts compared to the N-ER material. This was in line with the higher overall incidence of repeated syntactic structures, lower word variation (MLTD), shorter sentences and overall reduced number of words used in the ER texts compared to the N-ER versions. Significant differences in overlap (or co-reference) were not found when the measure was broken down to test for either noun or stem overlap.

Similarly, the measure for temporal cohesion (situation model) which is related to deep cohesion within texts, showed no significant difference between the ER and N-ER texts. This measured the use of tense and aspect to establish time and situation in relation to the reader and the text content.

To recap, the outcomes from Coh-Metrix measures demonstrated some strong significant differences between ER and N-ER material on linguistic features that affected surface level understanding of text. The measures supported the hypothesis that ER literature would be descriptively and syntactically less complex than its N-ER comparators. On measures that affected deep level understanding, there were additional significant differences revealed between ER and N-ER documents in lexical variation, overlap of terms and syntactic repetition. These further upheld the hypothesis that ER material would contain a lower variation of words and would demonstrate a higher use of co-referents (overlap). As expected, outcomes on lexical variability and the overlap of terms could be linked back to the impact of surface level features such as the common utilisation of familiar, frequently-used and concrete vocabulary, and the use of shorter words and sentences.

However, also as predicted, levels of cohesion within the ER texts compared to N-ER documents were more difficult to identify. Whether more cohesive devices were available within the ER versions that would help readers to make inferential links was inconclusive. Findings did not reveal whether cohesive devices in the form of increased repetition in the ER material provided a more cohesive and coherent document that was easier to understand than the N-ER versions. Indeed, both document groups revealed identical scores on LSA which demonstrated the same level of semantic overlap. These findings suggested that as cohesive devices, repetition of vocabulary and grammatical constructions dominated ER material as opposed to the type of cohesive devices possibly created through the use of a wider range of semantically related terms evident in the N-ER material that might be employed to elaborate content.

The following discussion contextualises these findings in relation to research literature and ER guidelines and outlines some implications for practice. Limitations of the study were also considered.

3.5 Linguistic Analysis discussion

While features have been given individual scores and measures, in practice they interact to influence the text on multiple levels, which in turn impacts on the reader's ability to grammatically decode and understand the information. Findings demonstrated different linguistic trends in the patterns of language used in ER as compared to N-ER texts. Whether these might contribute to a better construction of meaning was considered through an examination of each of the Coh-Metrix output measures.

Words and sentences

It has been established that attention to surface level features in texts (previously measured through readability scores in Study A: The Survey) can make a text 'easier' to read but not necessarily easier to understand. These features are more straightforwardly managed and manipulated than deep level features such as co-reference that involve more complex knowledge to manipulate and have a greater impact on text cohesion. The significantly reduced number of words and shorter sentences in the ER group was consistent with one of the main goals of simplification given in available ER guidelines (DoH 2010; Inclusion Europe n.d.; MENCAP 2002). This resonates with McNamara et al. (2011) who reported that shorter sentences were read more quickly and processed more efficiently for understanding by the average reader. Flesch Kincaid Readability measures on ER and N-ER texts (as indicated in Study A) were consistent with this surface level difference. However, the average level for ER was Grade 8, and for N-ER documents, Grade 14, both of which were well above the average reading age of the population with IDs, which has been estimated to correspond to Grade Level 2 (Morgan & Moni, 2008; Jones et al., 2006). Evidence from Coh-Metrix has demonstrated that the DoH ER material

under scrutiny in this study had undergone a process of simplification. Moreover, a similar number of sentences was maintained, while reducing the number of words used, suggesting that attempts were made to retain parity of structure across both ER and N-ER documents whilst simplifying content. The question of *how* simple ER material needs to be in order to match the estimated literacy skills of the majority of the IDs population remains.

If simplification is the end point, the ER material in this study could be described as having achieved its goal. However, proving that ER documents have achieved a form of linguistic profiling particularly focused on surface level features does not in itself make it useful or meaningful to its target audience. How people with IDs are able to process the information in ER material requires a more in depth consideration of the way language is constructed. Indeed, Fajardo et al. (2014) demonstrated that the use of shorter words and sentences in their ER news texts did not make any difference to how well the readers (with IDs) understood the news stories.

Word attributes

Vocabulary chosen by the author would be likely to have an impact on the construction of information for meaning by the reader, particularly if the reader's lexicon is limited or highly individualised. The Coh-Metrix data showed that the ER documents used significantly more high frequency, familiar, concrete and imageable words compared to N-ER texts. These supported the vocabulary choices found in ER material as being less difficult than those used in the N-ER texts. It further supported the idea that vocabulary choices found in ER material were less difficult to understand than those used in the N-ER text. Replacing abstract, less familiar vocabulary with more concrete more familiar words was also consistent with tenets of the guideline examples previously outlined in Study A: The Survey. However, there is a caveat here. Use of shorter simpler sentences made up of concrete, familiar vocabulary may mean a reduction in information, and may also affect the quality of the language used. Walmsley (2010; 2013) warned of the loss of nuance that went along with simplification processes in trying to compile ER versions of

research reports, and Crossley et al. (2007; 2012) have remarked that simplification has led to texts that missed out crucial information. They commented that modification resulted in less natural forms of discourse by reducing the natural forms of linguistic redundancy (repetition) that worked to help the reader understand text. It was perhaps unsurprisingly therefore that the use of more familiar words in Fajardo et al.'s (2014) study did not increase text comprehension in participant performance.

As mentioned, McNamara et al. (2010) have demonstrated that the use of high frequency, concrete words combined with low variation can successfully reduce the need for inference on the part of weak readers without IDs. (Lexical diversity was found to be significantly lower in the ER texts than in the N-ER comparators in this study). However, Crossley et al. (2007) also showed that the use of large numbers of high frequency words (often a result of low lexical diversity) correlated with a higher level of ambiguity (polysemy measure) in texts. In the current study, ER texts were significantly higher in polysemy than those that were N-ER. It follows that texts with high levels of ambiguity would be more difficult to understand and less coherent. For example, the use of words that were frequent in the English language such as the generic term 'people' might be used instead of specific terms 'neighbours, students, people with IDs, participants'. Combined with increased repetition of nouns and syntactic structures this could create a level of reduced information that may further limit meaningful content. It would be harder to make links and inferences from the text because there would be too many choices to be made about every ambiguous item. The resulting information would be general and superficial rather than specific.

Syntactic complexity

In terms of syntactic structures, ER material consistently showed a significantly higher level of repeated structures compared to those in N-ER texts despite the shorter sentence length. Thus repetition was found to occur at both word and syntax levels. Along with the previous surface level features discussed (shorter words, shorter sentences and word attributes that relate to lower lexical diversity), the presence of repeated syntactic

structures strengthened the likely effect of limited content. It indicated minimal elaboration of ideas that might otherwise have positively influenced cohesion and the construction of meaningful information.

The ratio of 'given' to 'new' information (G/N) showed that ER repeats 'given' information significantly more often than providing new information when compared to N-ER documents. Building 'new' information onto 'given' information is a common strategy identified by Crossley et al. (2014) and is used when creating texts in educational settings. In particular, readers with lower background knowledge benefited from this convention in their comprehension of reading material. However, the Coh-Metrix outcome in Study B did not show how the 'given' information in ER texts was organised, and whether it was only repeated rather than elaborated information. Again, significant findings related to low lexical diversity and high ambiguity in the ER texts suggested a tendency towards the repetition of 'given' information. This was probably less evident in the N-ER versions where there was evidence of comparatively more new information introduced.

The shared topic between ER and N-ER versions in the DoH document pairs implied a common vocabulary. Significantly reduced lexical diversity in the ER versions coupled with a significantly higher number of shorter sentences might explain the unexpected result of not finding any significant difference in semantic overlap (LSA) between ER and N-ER texts. It could be that ER versions used a significantly higher number of the *same* words rather than a combination of synonyms, elaborated terms and semantically-related words used in the N-ER versions.

Although the main verbs embedded in both versions at a similar distance into the sentences (no significant difference between ER and N-ER documents was revealed), complexity was countered in the ER texts by having significantly shorter sentences, which were less likely to impose a burden on memory. This could suggest that less effort might

still be required to read and understand the ER version because of the shorter sentences used.

Connectives

Connectives, used to link clauses and phrases (e.g. additive, causal, contrastive, temporal) occurred significantly more frequently in N-ER texts as might be expected due to the longer sentences evident. Achieving shorter sentences in ER documents (as suggested in the guidelines summarised in Study A. The Survey Table 2.1.1) precluded the varied use of connectives. As a result, linguistic links such as 'because', 'when', or 'but' were removed in the ER versions. Counter-intuitively, Crossley et al. (2012) showed that these were useful in supporting weak readers to make sense of text despite the consequential lengthening of sentences. It is not clear therefore, that ER texts were made easier to understand by the removal of cohesive devices in the form of connectives.

Fajardo et al. (2013), demonstrated that connectives previously tested and deemed 'familiar' to participants (e.g. additive connectives 'and' and contrastive connectives 'but') helped readers with IDs to understand ER material whereas less familiar connectives (e.g. temporal 'before, after' and causal 'therefore' 'because') did not. Again, while Coh-Metrix has provided an indication that fewer connectives were used in ER material compared to N-ER versions, questions remain about how far these were likely to encourage or inhibit better understanding of ER material.

Lexical diversity

Both TTR, and MLTD (McCarthy and Jarvis 2010) demonstrated a significantly lower variation of words present in ER texts compared to the N-ER versions. This suggested a trend for the repetition of terms rather than the use of synonyms or complex nouns in the process of simplifying language for ER texts. Theoretically, the lack of variation might help surface level understanding, but the question of information processing at a deeper level remains. Furthermore, the effectiveness of word repetition as an ER strategy would

only be useful if the meaning was transparent within the context of the document. Repetition of a term, delivered within a repeated syntactic structure as found in the ER documents analysed, risks narrowing linguistic scope and reduces linguistic opportunity within the text for the reader to construct meaning or to develop new knowledge.

Referential cohesion

On argument overlap (nouns and pronouns) ER documents showed significantly higher levels of co-reference between sentences. Co-reference has been identified by Crossley et al. (2012), Allen (2009), and McNamara et al. (2014) as one of the most common effective cohesive devices used in material simplified for educational purposes and in particular it can benefit weaker readers. Overall findings in Study B also showed a higher level of repetition evidenced in ER documents. This suggested that the ER versions should be easier for non-proficient readers to understand. However, questions emerged when higher levels of co-reference in the ER documents were considered alongside measures that showed low lexical diversity and high levels of ambiguity. Whether co-reference in the form of repetition in ER versions could effectively overcome the possible confusion created by the presence of many highly ambiguous words is not certain.

Noun and stem overlap, as mentioned, were not significantly different in ER and in N-ER versions. This suggested that the same number of key words had been maintained in both sets of documents. However, the N-ER versions contained a significantly higher number of longer sentences. Thus the repeated terms could be assumed in these versions to be separated by more words, allowing for the inclusion of connectives, explanatory terms and adjectives. In contrast, the same level of overlap in the numerous short sentences (as found in the ER texts) left little room for elaboration. A number of repetitions within short sentences (ER) may lead to more redundancy and more possible loss of information than the same number of repetitions in long sentences (N-ER). The nature of the words and terms used to create effective referential cohesion in both ER and N-ER documents and how the repetition of words affects cohesion could benefit from closer qualitative analysis.

Situation model (deep cohesion)

Temporal cohesion (tense and aspect) was expressed through use of verb morphology. This provides readers with linguistic cues to contextualise information in time, and in relation to themselves, the author and the world around them. It has been described by Kintsch (1988) as providing the information for a reader to generate a situation model from the text. Measures showed no significant difference between ER and N-ER documents on this indice although ER texts demonstrated a slightly higher incidence of temporal cohesion than the N-ER versions. It can be therefore argued that a similar cognitive ability would be required to process and situate information from either text version which implies limited gain to be had from ER material over and above N-ER material. This raises questions about how producers might better manipulate text structure to increase temporal cohesion in ER texts thereby increasing the chance of positive cognitive gain.

Overall cohesion was influenced in the ER documents by shorter sentence length, word choice (attributes), lower lexical variation and the reduced complexity of grammar. All of these features showed significant differences when compared to the N-ER versions. McNamara (2013) has demonstrated that specific cohesive devices such as co-reference, connectives and semantically related terms can guide the construction of meaning for readers. She argued that these cohesive devices facilitated low ability readers to reach a deeper understanding of information. Whether the ER material in this study might claim this success requires further analysis.

3.5.1 Limitations of Study B: Linguistic Analysis

This study was carried out using a purposive sample of ER texts designed and prepared by the DoH between 2000 and 2012. As acknowledged in Study A, the results therefore reflect documents produced by one organisation and over a limited time period. The use of automated software was useful for gaining detailed information from a large volume of

text samples. However, it was evident from the interpretation of results that certain qualitative aspects of text related to ambiguity and cohesion were only partially explored. For example, whether co-referencing through noun, stem and argument overlap was dominated by repetition has not been clarified. Furthermore, while word count and word attribute measures from Coh-Metrix provided an indication of text difficulty in terms of human ratings, they did not give qualitative information about the specific vocabulary that had been retained in the N-ER documents and omitted in the ER versions, nor the number of times that the same words had been repeated without any textual elaboration. Equally, the measures identified 'low frequency' words as unfamiliar vocabulary but to a particular target audience (such as adults with IDs), they could function as highly familiar words (and 'high frequency'). For example 'advocacy' or 'rights' could arguably be more frequently used by people with IDs than judged to be used by the general population. Finally, structural devices such as bullet points and headings were removed from both ER and N-ER text in preparation for analysis. The potential of such devices to contribute to successful reading and even to support effective understanding of written material has not been addressed in this study.

3.5.2 Conclusions and Implications of Study B: Linguistic Analysis

This analysis of linguistic features revealed clear differences between ER and N-ER DoH documents. The ER versions achieved a simpler level of language, particularly on surface level indices. There was less evidence that linguistic constructions affecting cohesion and coherence have been achieved so successfully. Shortened sentences, lexical containment and the repetition of words and syntactic structures, whilst apparently promoting surface level processing could in fact *compromise* understanding at a deeper level rather than *facilitate*. Outcomes showed that they resulted in reduction of information, increased ambiguity and loss of cohesion. Lexical cohesion plays a crucial part in conveying logical meaning through text. However, it is complex and influenced by the interplay of a number of linguistic elements. To a certain extent, producers of ER material have succeeded in creating documents that are linguistically simpler than their N-ER

comparators. However, a tension remains between the format of the simplified language used and how it functions to influence the construction of meaning.

Certain compromises to meaning have occurred as a result of the simplification processes mapped out in the ER documents analysed. The conventions used to simplify ER material can interfere with the cohesive structures that support inferencing and can negatively affect the overall coherence in a text. Thus, the question of how the nature and quality of information and meaning is preserved through its transformation from N-ER to ER versions requires further address.

3.5.3 From linguistic content to discourse

The linguistic constructs that influenced meaning at the level of discourse and coherence were difficult to capture with an automated analysis alone as undertaken in Study B. Reducing linguistic ambiguity and increasing explicit cues through careful use of co-referents should increase the probability that a clear message is expressed through text. As previously argued, explicit language reduces the cognitive burden required to create relevance from it (Wilson and Sperber 2002). Meaning could thus be constructed with less effort and uncertainty on the part of the reader. So far there is little evidence in academic literature to demonstrate that ER material is qualitatively distinct from N-ER material in that it fulfils its claim of reducing cognitive burden on the reader and being 'easier' to make sense of.

Most supporters of automated linguistic methods of analysis have acknowledged their restrictions in identifying qualitative patterns in text. Allen (2009) compared intuitive and structured methods of simplifying newspaper texts (n=80) for educational purposes by focusing on the construction of relative clauses. Computational analysis revealed that relative clauses were more often unmodified in the intuitively simplified texts, regardless

of their educational level. However, Allen (2009) argued that the influence of these subtle differences on cohesion and overall meaning could only be identified through a qualitative analysis. Indeed, Graesser et al. (2011: 223) in a review of manual and automated methods of linguistic analysis admitted that computer systems 'cannot identify and scale texts on all levels of linguistics, discourse and meaning'. Furthermore, they argued, for deeper critical analysis of text comprehension, human endeavour is required to incorporate an evaluation of crucial factors such as prior knowledge, inference mechanisms and the capabilities of the target readers. Bestgen et al. (2010) clearly demonstrated the differences between a latent semantic analysis (LSA) run by Coh-Metrix and that done by expert human effort. They graded two hundred and twenty three essays from second language learners by manual raters and by machine. Findings demonstrated a negative correlation between the two methods. This was explained because expert authors made use of specific strategies through their own subjective understanding and knowledge of potential readers' levels of language. Another reason given was that human raters were much more sensitive to a wider range of cohesive devices and their subtlety of meaning than computer software.

There is no evidence to suggest that the simplification of ER material is anything other than intuitive. How this affects the quality of meaning in ER documents compared to the N-ER versions has not yet been established. An analysis of linguistic discourse was therefore carried out in Study C. This looked at how linguistic terms and cohesive devices were used to represent people, events and actions in ER material compared to N-ER versions, and how the texts were organised within a functional linguistic context. This is presented in Chapter 4.

Chapter 4. Study C. Discourse Features. ‘Easy Read’ – simplification or reduction? Critical differences in the discourse of UK DoH ‘Easy Read’ literature and their ‘Non-Easy Read’ equivalents.

Following on from Study B: Linguistic Analysis, where reduced text cohesion was identified as one of the main unintended consequences of the simplification process, Study C: Discourse Features aimed to analyse this further by comparing the differences in discourse patterns found in ER and N-ER documents that could not be identified through automated processing. A systemic functional linguistic analysis was carried out on five pairs of DoH text excerpts. This involved an in-depth examination of the texts on three functional levels: textual, relational and interpersonal.

4.1 Background to Discourse Features

As referenced early on in the previous chapter (Study B. p. 118), Fajardo et al. (2014) found that increased co-reference (overlap of terms) negatively affected the reading comprehension of people with IDs, while increasing word frequency and reducing word length did not make any significant difference. This was contrary to previous findings (McNamara et al., 2010) where such modifications had a positive outcome on reading comprehension, particularly with weak readers. McNamara (2013) observed that cohesive linguistic features in written documents reduced cognitive load on the reader by providing explicit links and cues. Without these, the reader had to fill the gaps using inferences and contextual information which required: an efficient working memory (Nash & Heath, 2010); the ability to update information as one reads (Henderson et al., 2013); flexibility to inhibit irrelevant interpretations of ambiguous language (Numminen et al., 2002); and the ability to situate the information within the context of personal experience (van Dijk & Kintsch, 1978). According to Sperber and Wilson (1983), increased cohesion such as that identified by McNamara (2013) normally contribute to increased levels of explicit information and are thus easier to process in pursuit of relevance. While

McNamara et al. (2010) suggested that computational analysis could establish levels of cohesion in texts more reliably than readability measures, it can also be argued that depth and detail of meaning can be lost, especially in relation to interpretation and understanding. As demonstrated in Study A. The Survey, ER documents may have greater face validity due to lower textual density, shorter sentences and enhanced layout, picture support and larger font size compared to their N-ER counterparts, but whether ER documents offer easier reading and understanding for the target audience is not shown. Furthermore, there is little evidence that ER versions have succeeded in expressing information that truly represents what has been published in the N-ER documents.

Study B: Linguistic Analysis considered the proposition made by Crossley et al. (2007) that intuitively simplified language led to more complicated and unnatural-sounding text. Altering natural language redundancy (repetitions or overlaps) effectively removed the linguistic devices that helped readers to achieve a deeper understanding of information while it also increased levels of ambiguity. Moreover, Allen (2009) and Crossley et al. (2008; 2014) showed that consequent difficulties of interpretation as a result of ambiguity increased when more common English words were repeatedly used. Both increased repetition and higher levels of ambiguity were found in ER texts compared to the N-ER versions in Study B.

A comparative discourse analysis of texts allows them to be considered in terms of how language is used to realise meaning, and whether attempts to create more explicit meaning have been achieved effectively. Butt et al. (2003), writing about the functional study of language, argued that the discernment of distinct functions begins very early when children distinguish between spoken and written forms. They theorised that a child hears language used at home and identifies it as different to that used in school or in the playground. A recognition of how context shapes the different functions of language begins to develop. Intuitive experience generates the ability to moderate the use and expectation of language in different settings and to infer meaning from it. Butt et al. (2003) demonstrated that this knowledge provides an interface between people and the

way they engage with others in society. For example, a courtroom judge reading out a judicial sentence will not use the same words and phrases as those he would put in a letter to the five-year olds he coaches at football. Similarly, the type of language used in a courtroom in the USA might be distinguishable from that used in the UK. Quality of language is decided in part through an intuitive understanding of its function within the contexts of both culture and situation. The type of language used in ER material could not only affect the way in which a reader constructs relevance from the message, but the quality of the message itself (Sperber and Wilson 1986). Butt et al. (2003) argued that the analysis of these different functions in written discourse provided a systematic and robust method for revealing relevant subconscious knowledge conveyed through language. A systematic analysis of the functions of language within a particular context can help to reveal patterns of co-reference and how the text is structured, as well as other nuances such as the impact of vocabulary choice on meaning, the attitude and stance taken by an author, and how the author interacts with the reader.

Systemic functional linguistics (SFL) is part of the school of 'discourse' methods. It is concerned with how patterns of language, in written or spoken texts convey particular representations of reality and shape the relationships between discourse producers and discourse consumers. In contrast CA focuses on capturing 'talk in interaction' (Ten Have, 2007: 174) as demonstrated in work carried out by Mander (2013) (see p. 69). Within SFL, patterns and trends are identified and analysed based on obligatory structural elements (linguistic) and the system of choices made by the authors to create meaning (Butt et al., 2003). As an analysis of functions bound within the context of linguistic structures and semantics, it served the purpose of a comparative investigation into the text-based material in the current study. It aimed to fill a gap in research to demonstrate whether ER documents are representative of their N-ER comparators in terms of maintaining the the overall coherence of the work, the quality of information and the voice of the original author. It might be assumed that authors of ER material worked to achieve parity in terms of information quality and type across the two document types. MENCAP (2002:6) have suggested in their ER guidelines that 'unnecessary detail' should be removed whilst maintaining the important information, and Walmsley (2010) has outlined the differences

in detail between ER research summaries and N-ER research articles despite the will to conserve the content. She talked of how she adapted the abstract for a study from life story experiences of women with IDs in relation to 'caring'. Unable to communicate the complex central tenet of her research, which was that 'women with disabilities have a complex relationship with 'caring', as both cared for and carers, and they are sometimes denied the opportunities to care afforded to other women', she was resigned to deliver a more limited impression of her participants' stories (2010:35).

Textual coherence relies on the way that cohesive devices such as co-referents, connectives and the overlap of terms are used and how they interact throughout a text (as identified in Study B: Linguistic Analysis). It will also be influenced by the way the topic is developed. How language flows to connect ideas logically will progress the 'story' from beginning to end. Beck et al. (1984) significantly increased forty-eight seven and eight year olds' understanding of texts by making connections more apparent, and by clarifying and organising actions and events sensitive to the syntactic, semantic and narrative context of two stories. Their research involved adapting text features through use of professional expertise and skill, and filling potential knowledge gaps with a view to the overall context of the story rather than following a rigid linguistic standard. In a later study, Beck et al. (1991) demonstrated how manipulating causal connections in four texts given to eight and nine year olds (n= 85) improved the quality of their understanding. They were able to demonstrate an ability to describe the chain of events rather than simply recalling the text. However, the text adaptations that were made by Beck et al. (1991), while increasing ability, also raised the Flesch Kincaid Readability Scores of the four text segments by a whole year which demonstrated that sentence and word length were probably increased. Crossley et al. (2007) have also shown that using a text with well-placed cohesive devices was more coherent, followed a meaningful progression and proved less demanding for weak readers. However, as Fajardo et al. (2014) showed, cohesive devices in the form of repetition might not always improve the construction of meaning through text. ER DoH texts analysed in Study B did demonstrate high levels of cohesion through repetition. A closer investigation of how cohesion in ER and N-ER texts contributes to overall coherence is therefore warranted.

In relation to cohesion the examples above have demonstrated that the task of simplification can run counter-intuitive to the aim of conveying meaningful information. As demonstrated in Study B; Linguistic Analysis, the representation of events and concepts in simplified documents is informed by the choices that authors and producers make about language. Results from the Coh-Metrix data showed that authors who produced ER material chose vocabulary that was measured as more concrete, higher frequency, more familiar and more imageable than those preparing the N-ER material. Several researchers involved in the creation of ER material have given examples of abstract complex concepts that have inherently resisted simplification. As previously elaborated in the introduction (p. 46 and p. 69), attempting to represent ideas such as 'citizen' (Walmsley, 2010) and 'meeting' (Grove, 2014) in a simplified version can be problematic because they cannot easily be replaced with highly concrete, imageable (easily visualised) alternatives that preserve the meaning of these terms. Such reduction of content can lead to perceived differences between the information represented in an original N-ER version and its ER comparator. Alongside possible reduced cohesion due to high levels of repetition, variations in the way that people and events are represented (vocabulary choice) may lead to qualitatively different interpretations of the message. If that message is abstract and conceptual as opposed to factual, the act of translation to a simpler version may affect meaning and agency, a point made by Walmsley (2001) in differentiating between 'inclusive research' and 'empowering research' for people with IDs. She cited Shakespeare (1996 in Walmsley, 2001) who made a distinction between what might and might not be inherently 'accessible'. An acknowledgement is made of the tension between the aim of simplification and the risk of reducing relevant, important information to a meaningless state.

Theories and concepts and social reality itself will often be complex, nuanced and difficult. If Disability Studies is to capture this richness, it will have to be able to use ideas and develop analyses which may not be transparent and simple. (Shakespeare, 1996 in Walmsley, 2001:201).

Author stance in relation to the target audience can also be reflected in language use. Pronoun choice and the selection of adjectives can add nuance or attitudinal emphasis to those positions. Chinn (2014) explored the role of ER texts within a health literacy framework and explained how the linguistic impact extends beyond presentational features and even surface linguistic features. She suggested they should be examined 'linguistically to see if they advance particular social identities' and argued that for people with IDs, 'these identities could be as passive recipients of health information and instruction or as active directors of health care and decision making' (2014: 256). Similarly, Rudd et al. (2013) maintained that one of the ways to avoid inequities in relation to 'access' to information was to ensure that documents produced for adults were written in an adult tone. Notwithstanding, they also entreated authors to build text with the lowest reading level possible. Managing these directives, whilst also creating a coherent text presents certain challenges.

4.2 Study C: Aims and research questions

ER material purports to represent the N-ER versions, despite the level of abstract information they may contain. Both are frequently published together and share the same or a similar topical title. The subtleties that differentiate between overall coherence, the vocabulary chosen to represent events and actions and author stance between the two document types may result in ER versions that are very different in the quality of the meaning they convey when compared to the N-ER original documents.

Study C: Discourse Features, aimed to examine the comparative functional discourse features in ER and N-ER material and to identify the effects of the simplification process on the discourse of ER material. Primarily, the analysis aimed to focus on the unintended outcomes of text simplification on cohesion through increased repetition combined with low lexical diversity. Further unintended outcomes relating to language choice and author position were additionally considered. Text-based discourse analysis grounded in

Systemic Functional Theory was used to explore the linguistic effects of simplification paying specific attention to the following research questions:

1. How is the overall coherence of the N-ER texts maintained in the ER versions (e.g. contextual relevance and informational salience)?
2. To what extent do the language choices made in ER versions replicate: a) the representation of reality provided in the N-ER versions of texts (e.g. levels of agency and responsibility assigned to key stakeholders)? b) the author's original level of engagement with their readers (e.g. forms of address and the power relationship) ?

4.3 Discourse Features method

Text sampling and preparation

The sample comprised the same forty-one ER documents and their N-ER counterparts sampled previously from the pool of thirty-seven pairs identified on the DoH website using specific search terms (See Study A: The Survey p. 86). The names of these documents are listed in Appendix Chapter 2. i The Survey, DoH Documents. Exclusion criteria applied to pages of text, matching for titles and content of text excerpts followed the same procedures as those given in detail in Study A: The Survey method (p. 86) and used in Study B: Linguistic Analysis (p. 121).

Once all documents had been matched for content and excerpts identified and coded, five document pairs were selected through stratification according to the Flesch Kincaid Readability scores obtained in Study A. The two texts with the lowest scores, the two that scored the highest and the two median scoring ER texts, were selected. These, along with their corresponding N-ER versions were then randomly sampled using an online electronic randomiser (Research Randomizer) to select text excerpts as in Study A (p. 87).

Bullet points, headings and sub-headings were removed, but all other punctuation (e.g. question marks, inverted commas, hyphens) were included, as well as indicators of new paragraphs. All five ER excerpts were then analysed using SFL alongside their N-ER comparator excerpts. Final analyses were independently rated by the researcher and a colleague for purposes of inter-rater reliability. Discrepancies were resolved through discussion. All ten annotated excerpts and their full analyses can be found in Appendix Chapter 4. i-v Discourse Analysis Texts 1-5. Table 4.3.1 provides the document titles of the five text pairs sampled for discourse analysis, the codes allocated to each document for this study and their Flesch Kincaid Grade Scores. (The original document codes that correspond to those in Appendix Chapter 2. i Survey DoH Documents are provided directly after each title. However, numbers one to five were applied to documents in this study (Study C) to allow for easier differentiation between texts.)

Table 4.3.1 Document names and codes for discourse analysis

Document codes Study C¹	Document title with original code (published by The Department of Health, UK)	Flesch Kincaid Grade Score
1E	Questions to ask when you go to the doctor or hospital (2007) 10E	5
1N	Questions to ask (2007) 10N	6
2E	All about personal health budgets (2012) 27E	5
2N	Understanding personal health budgets (2012) 27N	11
3E	Caring for our future. Reforming care and support (2012) 45E	7
3N	Caring for our future. Reforming care and support (2011) 45N	12
4E	Valuing People Now; The Delivery Plan 2010-2011 (2010) 40E	11
4N	Valuing People Now; The Delivery Plan 2010-2011 (2010) 40N	18
5E	Valuing People and Research: Learning Disability Research Initiative (2007) 34E	14
5N	Valuing People and Research: Learning Disability Research Initiative (2007) 34N	22

¹E = Easy read N= Non-Easy read

Analytical approach and process

In order to document some of the more ideological and interactional aspects of the simplification process that are missing in the quantitative and automated analyses mentioned previously, a detailed SFL -based discourse analysis was performed on a sample of ER documents and their N-ER counterparts. This enabled a comparison between the linguistic choices in the original and simplified texts according to three main overlapping functional parameters. Halliday and Matthiessen (2004) define these with referential function first, then interpersonal function and finally textual function and both ER and N-ER texts were analysed accordingly as represented below. However for the purposes of reporting the results in this study, the order has been adjusted to consider the cohesive devices first within textual function. Referential and interpersonal functions are then described and discussed. How cohesion and coherence was developed throughout these is also accentuated.

- a) Referential function considers the kinds of words that are used to represent the reality of the 'story'. This refers to who or what is being represented in the text (the PARTICIPANTS, expressed through nouns, noun phrases and pronouns) and doing or being what (PROCESSES, expressed through verbs, verb phrases) and where, when, how and why (CIRCUMSTANCES, expressed by adverbs and prepositional phrases or subordinate clauses). These choices in the case of ER documents, have been made with the core aim of simplifying the language. Any shaping of the ideological content of the texts in terms of the levels of agency and responsibility assigned to key stakeholders could be an unintended outcome of this process.

To examine referential function, each text excerpt was systematically annotated, firstly highlighting all nouns, pronouns and noun phrases, then all verbs and verb phrases and finally all adverbs and prepositional phrases. Examples of annotation applied to Documents 3E and 3N-ER is given below in Figure 4.3.1 where nouns are identified in blue, verbs and verb phrases are in black and adverbs and prepositional phrases are shown in orange for both the ER and the N-ER text. Annotated texts for all ten document

excerpts on every function can be found in Appendix Chapter 4. i Discourse Analysis Texts.

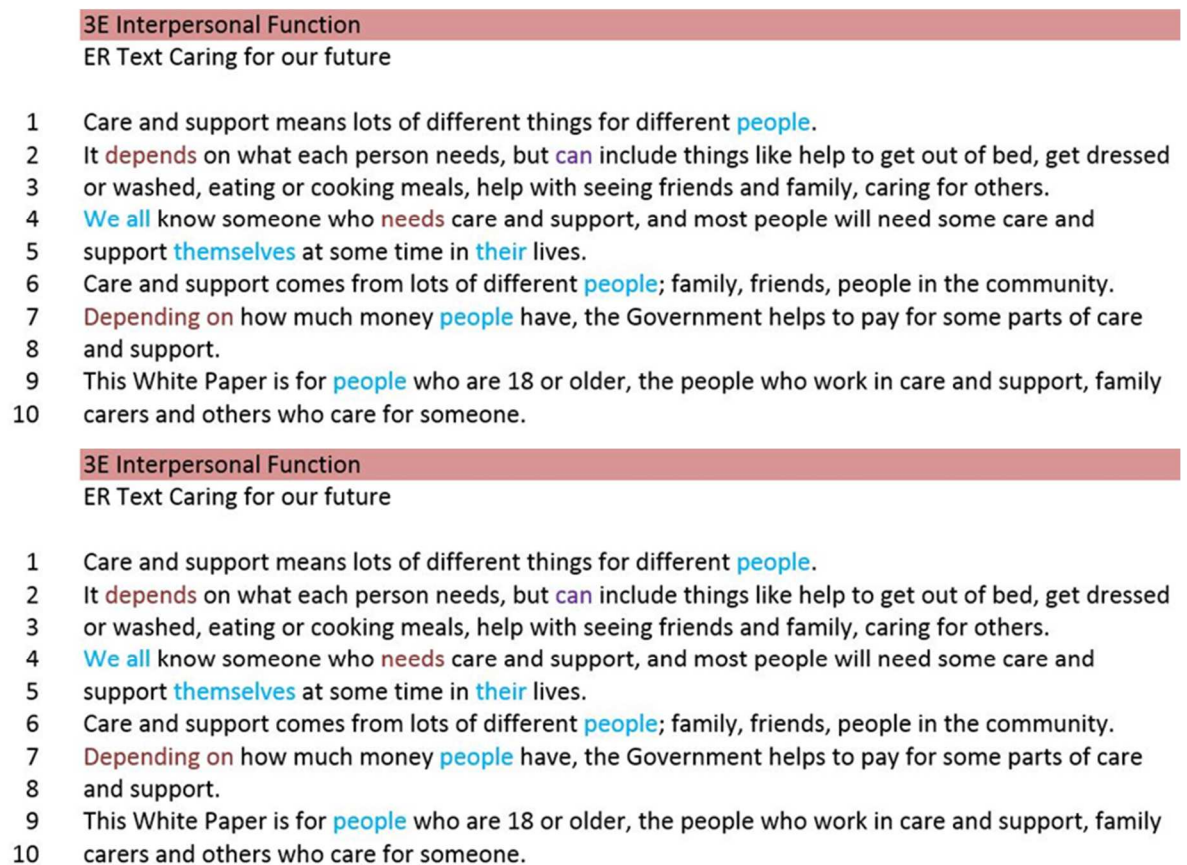
Figure 4.3.1 ER and N-ER text example annotated for referential function

3E Referential Function	
	ER Text Caring for our future
1	Care and support means lots of different things for different people .
2	It depends on what each person needs, but can include things like help to get out of bed, get
3	dressed or washed , eating or cooking meals, help with seeing friends and family , caring for others .
4	We all know someone who needs care and support , and most people will need some care and
5	support themselves at some time in their lives .
6	Care and support comes from lots of different people ; family, friends, people in the community .
7	Depending on how much money people have, the Government helps to pay for some parts of care
8	and support .
9	This White Paper is for people who are 18 or older, the people who work in care and support , family
10	carers and others who care for someone
3N Referential Function	
	N-ER Text Caring for our future
1	Care and support enables people to do the everyday things that most of us take for granted: things
2	like getting out of bed, dressed and into work ; cooking meals; seeing friends ; caring for our families ;
3	and being part of our communities . It might include emotional support at a time of difficulty or
4	stress , or helping people who are caring for a family member or friend . It can mean support from
5	community groups and networks : for example, giving others a lift to a social event .
6	It might also include state-funded support , such as information and advice , support for carers,
7	housing support , disability benefits and adult social care . Care and support is something that
8	affects us all: 76 per cent of older people will need care and support at some point in later life . We
9	will all know someone , a family member or friend , who needs some extra care or support to lead a
10	full and active life .

Texts were viewed side by side and where appropriate, systematic comparisons were made of the way that repeated nouns, verbs and adjectives (and noun, verb and adjective phrases) represented people and events in ER versus N-ER texts with a view to evaluating how any repetition (or linguistic co-reference) might enhance the construction of understanding for the reader or hinder it. Comparisons were also made of the differences between texts on qualitative aspects of vocabulary choice and syntactic arrangement that resulted from linguistic simplification.

- b) Interpersonal function relates to the ATTITUDE and voice of the author in relation to the reader. This can be expressed by choice of personal pronouns, modal or explicitly evaluative expressions. Readers may also be addressed more directly through the use of interrogatives and imperatives, as against declaratives. Through these choices the authors of the texts adjust their position to the readers (e.g. in terms of formality, authority and power relations). Again, the intention to simplify language on the part of the ER author could demonstrate unintended differences in the voice used to relate to the ER reader compared to the voice used to relate to a N-ER reader.

Figure 4.3.2 ER and N-ER text example annotated for interpersonal function



To examine interpersonal function, each text excerpt was systematically annotated, firstly highlighting references directed to the reader, through use of pronouns or nouns or co-reference made to these (in blue), then all evaluative words and phrases (red) and finally any modal verbs used (in purple). Following on from the previous example, Figure 4.3.2

provides the annotated text for excerpts from Documents 3E and 3 N-ER. Again, all other annotated texts can be found in Appendix Chapter 4. i Discourse Analysis Texts.

As before, texts were viewed side by side. These were compared on the choice of words used to directly or indirectly refer to the reader and how repetition of these (co-reference) affected cohesion and ultimately changed the depth of meaning in different text types. How evaluative and words modal verbs further affected this relationship was also observed.

- c) Textual function relates to the overall effect or impact of the text structure on the meaning conveyed. A text may, for example, be constructed in the form of an argument to be persuasive or as a narrative piece with the purpose of entertaining. Overall textual COHESION affects the function of a text and can be analysed by looking at the number of lexically and grammatically related words in the piece, and also by considering the level of repetition and summary that helps the reader to relate back to previous sections of the text. The textual function of a text also has a cognitive aspect; overall COHERENCE of the content often assumes a shared contextual knowledge of the topic addressed.

To examine textual function, each text excerpt was systematically annotated wherever linguistic links could be identified that helped the reader to make sense of the text as it progressed. These mainly took the form of cohesive devices (co-reference) such as the repetition of terms or the use of pronouns to make reference to previously named concepts, events or people. Figure 4.3.3 provides the text excerpts from Documents 3E and 3 N-ER annotated for textual function in green. As before, all other annotated texts can be found in Appendix Chapter 4. i Discourse Analysis Texts.

Figure 4.3.3 ER and N-ER text example annotated for textual function

3E Textual Function

ER Text Caring for our future

- 1 Care and support means lots of different things for different people.
- 2 It depends on what each person needs, but can include things like help to get out of bed, get dressed
- 3 or washed, eating or cooking meals, help with seeing friends and family, caring for others.
- 4 We all know someone who needs care and support, and most people will need some care and
- 5 support themselves at some time in their lives.
- 6 Care and support comes from lots of different people; family, friends, people in the community.
- 7 Depending on how much money people have, the Government helps to pay for some parts of care
- 8 and support.
- 9 This White Paper is for people who are 18 or older, the people who work in care and support, family
- 10 carers and others who care for someone

3E Textual Function

ER Text Caring for our future

- 1 Care and support means lots of different things for different people.
- 2 It depends on what each person needs, but can include things like help to get out of bed, get dressed
- 3 or washed, eating or cooking meals, help with seeing friends and family, caring for others.
- 4 We all know someone who needs care and support, and most people will need some care and
- 5 support themselves at some time in their lives.
- 6 Care and support comes from lots of different people; family, friends, people in the community.
- 7 Depending on how much money people have, the Government helps to pay for some parts of care
- 8 and support.
- 9 This White Paper is for people who are 18 or older, the people who work in care and support, family
- 10 carers and others who care for someone

Texts were viewed side by side. Co-reference (repetitions, use of pronouns, use of synonyms) was compared between the two document types, with close consideration of how often words were repeated, when elaboration was evident, and how this affected the construction of meaning and overall coherence of information expressed in each. Narrative elements such as a clear beginning, middle and end were identified and how themes and topics were introduced were also noted.

Relevant discourse features

In summary, the linguistic choices in N-ER and ER DoH texts were analysed with particular attention to trends in textual, referential and interpersonal functions. Textually, the structure of the text was analysed with attention to the effectiveness of cohesive elements used and whether these combined to reproduce the original purpose of the text

(e.g. persuasive or simply informative) and whether coherence was reliant on simple repetition of terms or on an elaboration of meaning for the reader. A text providing informational instruction (expository), such as those analysed from the DoH in this study was defined McNamara (2013), as one that contains new information for the reader. She demonstrated that informational texts tend to include more unusual vocabulary and to incorporate more referents, but they tend to use less complex syntax than narrative or persuasive texts.

Referential function characterised the way that different participants, events and circumstances were referred to in the text. It was expected that the main participants in these government documents would include NHS authorities, health and social care professionals, Social Services or Government bodies and the public (people with and without IDs). How these were co-referenced within the text excerpts (through repetition or through more diverse use of synonyms and pronouns) provided further evidence of how vocabulary choice shapes meaning within a text. Furthermore, expressions of the roles of the participants through the combination of nouns/ pronouns and verb phrases (and how they were co-referenced) framed the level of agency ascribed to the reader. The way events and circumstances were described demonstrated whether ER texts were written with or without ascribing a reduced level of agency to the reader.

Finally, it became evident that as a result of the simplification process, specific framings of the reader's status in relation to the author could be differentiated in the two document types through the way the reader was addressed. The positioning of author and reader were often represented by use of 1st, 2nd and 3rd person pronouns. 'We' represented the inclusion of the author within processes whereas 'they' and 'you' separated them from the author and reduced levels of agency within the text. Observations of unequal power relationships were also identified through the choice of evaluative expressions of attitude (or lack of them) attributed to the readers. These included feelings or states of being (e.g. fear or happiness) and conveyed assumptions on the part of the author.

4.4 Discourse Features results

All five ER texts analysed were shorter in length, used simpler syntactic structures resulting in shorter sentences, with more concrete and high frequency vocabulary than their N-ER comparators. However, a closer inspection of linguistic representations using SFL at a deeper level revealed some problematic aspects. The findings are presented with reference to the five text pairs numbered 1 to 5 and labelled E for ER (e.g. 1E) and N for N-ER (e.g. 1N). Line numbers indicated by L are given to cross-reference examples within the context of full text samples (available in Appendix Chapter 4. iv Discourse Analysis Texts). Although it was useful to review any relevant expressive differences by the main three language functions (textual, referential and interpersonal), a focus on the way that cohesive devices have been used to develop coherence in the text excerpts incorporates the recognition of significant shifts in representation at the level of power and agency. A review of the three areas typically implicates recombination at all three functional levels. This is taken into account in the summary below.

Textual function

The intuitive simplification of texts impacted on text structure in all five ER versions compared to their N-ER equivalents. Trends were identified in overall coherence through patterns of lexical cohesion, the simplification of syntax, the staging of information and where reference was made to elements external to the immediate text.

Repetition of terms as a tool for lexical cohesion was used in all five ER versions, each with similar consequences. As previously identified, repetition of 'care and support' served to reduce the amount of new or explanatory information that might have aided understanding in 3E. Similarly, 'research' or 'researcher' in 5E was reiterated four times in the final phrase: 'knowing how to make the research help both researchers and those they research without the research having a bad effect on either group' (L 16, 17). The understanding of this phrase relied on the reader having a good prior understanding of 'research' as there was no other semantic link given in the immediate text to provide

cohesive cues for the various manifestations of 'research'. The term was further syntactically complicated by being embedded within a passive construction 'those they research'. In both cases, (3E and 5E) repetition narrowed the terms and led to ambiguity. 5N, on the other hand, provided a better level of lexical cohesion through use of co-reference around the term 'research' that did not entail high levels of repetition (e.g. L 1) but did use elaboration of the terms e.g. 'research process' (L 5), 'research proposals' (L 8).

Simplified syntactic forms in 4E (introducing employment policy) showed succinct and direct use of language. However, repeated use of the abstract term 'The cross-Government team' (L 5-9) and the other participants 'Getting a Life Programme' (L 5), 'Project Search' (L 7) and 'the new Employment project' (L 8) were difficult to understand without the accompanying explanations that were given in 4N. A complex list of policies and procedures made up a large part of 4N. These were expanded through a range of relational processes represented through the use of verbs 'to develop' (L 28, 30), 'promote' (L 32), 'will be updated' (L 33), 'will be published' (L 33), 'will lead to' (L 36), and 'will target' (L 38). In contrast, the ER version relied solely on three repetitions of 'will support' (L 7, 8, 9) and two repetitions of 'will work' (L 3, 9), which vastly reduced the scope of the text and the possibility of gleaning useful information from it. The brevity of 4E (six lines in total) compared to 4N (twenty-four lines) also affected the development of the topic. 4E did not outline a rationale for the new policy on employment whereas, 4N began the text stating 'Having a real, paid job that you enjoy is the best route to a full life' (L 1) which provided context and situation to the text.

Similarly, the ER text on 'research' (5E) began with 'Our Health, Our Care, Our Say said the Government would work with the Disability Rights Commission on deciding on the best services' (L 1), this did not point the reader to 'research' as the main theme. In contrast, 5N opened with a description of the 'LDRI' (L1) as 'a bold initiative in providing an inclusive approach to research commissioning and research management' and did not assume previous knowledge from the reader as the comparator ER version seemed to

do. A further example of weak cohesive cueing was found in text 1E where the reader was required to make a contextual temporal leap into the future to consider 'your next appointment' (L14). 1N provided better textual cohesion through a narrative structure contained within the *current* doctor's appointment which could place less cognitive demand on the reader than the ER version. Similar demands were made in 3E where the reader was expected to process new information about 'This White Paper' in the final line of the text (L9). As new information with no apparent link to given information, it interfered with overall coherence. The White Paper was not mentioned in the sample from 3N where textual coherence was better maintained.

Referential function

The simplification process resulted in ER material containing a reduced variation of words that were repeated rather than elaborated through a diversity of vocabulary. There are examples of where reduction and repetition of references made to people, events and actions (unintentionally) created patterns of disempowerment. In 3E, 'Care and support...can include things like help to get out of bed...' (L 2-3) replaces 'Care and support enables people to do...' (3N/ L 1). 3N, furthermore, extends the 'enabling' process to provide examples of how 'care and support' empowers people to 'get[ting] out of bed...cook[ing] meals...see[ing] friends....car[ing] for our families...be[ing] part of our communities' (L 2-3). In 3E, on the other hand, the emphasis is on the 'help' needed by people with IDs: 'help to get out of bed, get dressed...help with seeing friends and family' (L 2-3).

The only text pair that did not follow a similar pattern of repetitive cohesive devices (that could further construct a power imbalance) was 5E and 5N which were about the Learning Disability Research Initiative (LDRI). Roles were ascribed in 5E to people with ID in 'research', reducing the potential power differential through the use of a number of active processes: 'work', 'decide', 'visited', 'found', 'used' 'collect' (L1, 2, 5, 7, 8). Less emphasis on ascribing roles to people with ID was apparent in the N-ER version where instead, the process 'research' took a lead role. Here, the idea that 'people with learning

difficulties can play important roles in commissioning research' came later in L 6, was mediated by the modal 'can' and dominated by the more powerful reference to research through use of 'LDRI study' (L 6) which preceded it.

Differences were observed in the way that people with IDs were represented in both text types and this was also affected by the combination of increased repetition and reduced lexical diversity in the ER versions. Perceived needs and requirements of readers were, for example, represented by processes in both 1E and 1N that were dominated by the repetition of imperatives 'ask' and 'write' with reference to dealing with a doctor's appointment. However, the repetition of 'ask' was almost doubled in 1E (L 1, 2, 3, 4, 5, 8, 10, 14, 15), suggesting that people with IDs are less likely to 'write' than the N-ER population. For example in 1E, 'Ask your doctor' (L 1), '.....ask a friend' (L 2), '...don't be afraid to ask' (L 3), '...ask the doctor to explain' (L 4) '...you could ask the doctor to write down any difficult words' (L 4). In contrast, the same lines in 1M read 'Write down....' (L 1), '....List or bring' (L 2) '...Write down details' (L 3) '....Ask your hospital' (L 5), '....Ask a friend or family member' (L 6).

The dominant use of repeated words in these examples led to a suggestion that target readers of ER material required more direct advice and more explicit information than those reading the N-ER version. While this might in fact be the case, further assumptions were made through the negative framing of conditionals in this text where the reader was reminded that 'If you don't understand any words....' (L 3), 'If you do not hear quickly about your next appointment...' (L 13), 'If you don't get the results when you expect...' (L 14), then there might be negative outcome.

Negative framing of conditionals was apparent in both texts, but was more evident in the ER version. It contrasted with the N-ER version 1N where it was less evident, e.g. 'Write down your two or three most important questions' (L 1), 'List or bring all your medicines' (L 2), 'Write down details of your symptoms' (L 3), 'Book any texts that you can and put

the dates in your diary' (L 16). The negative framing of conditionals implied that while both sets of readers might find the doctor's appointment difficult, those who used the ER version were likely to find it more difficult than those who read the N-ER version.

Also as a result of the simplification process for ER material where complex words are replaced with more concrete and familiar vocabulary, clear differential representation of power is evident. 2E and 2N looked at personal health budgets. In 2E, the readers' options were repeatedly made conditional on external NHS approval in four cases (L 2, 7, 10, and 13) (e.g. 'if the local NHS agrees this meets your needs they arrange the care and support for you' (L 7). This suggests that the locus of control lies with the NHS, and has the effect of reducing the joint decision-making process that is represented in the corresponding N-ER version (2N) in which the agreement is presented as mutual (e.g. 'A personal health budget is... planned and agreed between you or your representative and your local NHS team' (L 1-3). Joint agreement and decision-making is mentioned four more times in 2N (L 5, 15, 18, 20-21) but never in 2E possibly due to the simplification of these terms..

Indeed, strong power differentials were identified in many of the processes represented in four out of the five text excerpts analysed. This was clearly shown through the levels of agency ascribed to people with ID. In 1E the reader was encouraged to ask: 'I would like to see copies of these' (L 11) with reference to accessing medical information written about them. Here the use of a tentative modal construction 'would like' reduced the level of agency compared to the N-ER version (1N) where the word 'entitled' was used: 'Ask...for copies of letters written about you – you are entitled to these' (L 15). Here also, through the choice of a simpler word to replace 'entitled', the unintended outcome has been to distance the two versions in terms of reader agency.

Similarly, in 2N more agency was ascribed to the reader, evident in the action process of 'agreement' embedded in the description of care and support: 'They [NHS] will then

arrange the agreed care and support' (L 17). 'You' was presented as an active participant in: 'you get the cash to buy the care and support you and your local NHS team decide you need' (L 20). However, in 2E, the notional budget category linked the money with the author as well as a neutral agency: 'we tell you how much money there is' (L 6) and 'we give you the money' (L 12). The use of the 'we' here could be the result of a convention to reduce linguistic complexity by avoiding the use of 'agreed care and support' or 'your local NHS team'. Unfortunately, the identity of the 'we' that exercised the power of 'giving' here is not clearly established and meaning has thus been reduced in comparison to the N-ER version.

Interpersonal function

Author stance and the consequent positioning of the reader was conveyed particularly through the use of 1st, 2nd and 3rd person pronouns, modal expressions, intensification and choice of mood (declarative, interrogative or imperative). Framing of this relationship may also have suffered some negative consequences of the conventional simplification of language that has reduced lexical diversity, thus creating a reliance on the repetition of vocabulary. This was particularly evident in relation to representations of agency. Author stance and expression were shown to reinforce power differentials between the author and reader in ER texts when compared to the N-ER versions, although to varying degrees.

4E and 4N addressed the topic of employment for people with IDs. In 4E, 'The cross-Government team', seemingly allied to the authorship, was repeated several times at the beginning of four out of five short sentences in relation to third party 'young people (L 6), 'people with complex needs (L 8) and 'people with learning disabilities and family carers' (L 9). In contrast, in 4N, the term 'cross Government valuing employment now team' was not used until L 21 and the pronoun 'we' was evident as early as L 1, which not only had the effect of providing more information for the reader, but it reduced the initial impression of power differential between author and reader.

In both texts 1E and 1N readers were informally addressed by 2nd person pronouns 'you' and possessive determiner 'your'. However, the high incidence of verbatim questions provided for the reader to use a hypothetical doctor's surgery situation in the ER version subordinated the reader. These verbatim questions could be the result of narrow word variation and increased repetition and were not present in the N-ER version. First, 2nd and 3rd person were also repeatedly used in 2E, although it is not clear who the personal pronoun 'we' (L 5, 6, 12, 15) referred to. It implied another layer of generic control imposed between the reader and the NHS (which has full control). Contrastively, in 2N there was joint decision making between the reader and the NHS which provided specificity of meaning and more information. The repeated use of the intermediary 'we' was not used.

Again, the differences in the choice of language reflected attempts to simplify linguistic complexity and to reduce the number of words being used in the ER versions. This had an impact on the way that obligation and the use of modal verbs were used in the two types of text and this affected meaning and the way that the reader was positioned in relation to the author.

Obligation was suggested more strongly in 2E than in 2N by the auxiliary verb 'must' and 'have to': 'you *must* spend' (L 1) 'NHS *has to/must* agree' (L 2, 13). This, combined with the statements 'We tell you...' (L 6), 'You say how you want us [to spend the money]' (L 6), 'We give you [the money]' (L 12), 'We think [personal health budgets could work...]' (L 5), and prepositional phrase '[...arranges the care and support] *for you*' (L 7), '[...buys the care and support] *for you*' (L 8), '[...looks after the money] *for you*' (L 9), created a relationship between 'you and us' where the power was located with the 'us' of the author rather than with the reader. There were no instances in 2N where 'for you' was used in this way and there were relatively few examples of obligation

Author use of 'we' and 'us' (L 1, 8) in 3N also suggested an inclusive stance that was not apparent in 3E where more distance was created by use of 'we' and 'themselves' and 'their' (L 4-5). Modal verbs of uncertainty were used three times in 3N in tentative exploration of the support and care that 'we' might need, e.g. 'It can mean support from community groups and networks' (L 4) and 'it might include emotional support' (L 3). This allowed the reader 'us' a level of shared choice along with the author. In contrast, a similar modal verb of possibility was used only once in 3E: '[it] can include things like...' (L 2), and this was framed by a condition 'It depends on what each person needs' (L 2), which despite reducing complexity in the sentence, weakened the agency attributed to the reader.

4.5 Discourse Features discussion

A qualitative analysis of textual, referential and interpersonal functions of ER and N-ER texts showed an overall reduction of words, sentences of much shorter length, and less complex syntax in the adapted versions. The ER versions were found to have poorer textual structure and weaker cohesion (often due to being repetitive), and they were less coherent, requiring higher cognitive skill to make sense of the content. By having a lower diversity of words, the scope and content of ER documents were naturally reduced. This not only affected text cohesion, but precluded the addition of evaluative words and phrases that brought interest and nuance to N-ER documents. However, the simplification process also appeared to affect *the way* information was represented in the documents. Imperatives and directives were used more often in ER versions, with more conditions (for making decisions) being imposed on the reader. A strong power differential was created through reduced agency attributed to people with IDs in nearly all ER text samples and this tendency was further reinforced through an author stance that often subordinated the reader.

Creating a less complex ER version complies with the minimum requirement for making reasonable adjustments to information (Turner & Robinson 2011), although the ER

documents did not always reflect the same level of overall coherence, positive representations of participants, or author stance that were established in the N-ER counterparts. Text simplification and its influence on representations appeared to be affected partly by the nature of the text itself (McNamara 2013). For example, the original version of 'Questions to Ask' is a short information leaflet aiming to provide step by step advice on how to manage a doctor's appointment. It related to a common and familiar activity experienced by most adults in the UK. By addressing a familiar topic, the text is likely to activate prior knowledge more quickly and easily for everyone (McNamara 2013). Thus it required fewer cohesive cues and the referential function of the language used was less affected, making it easier to simplify.

In contrast, the original version of 'Valuing People and Research' was a much longer text sample, discussing a more abstract and less familiar topic. Prior knowledge activation may occur more slowly with an abstract topic and, therefore, the reader would require more explicit information to make sense of co-referents, backed up with examples in the text. Such a document may be harder to simplify because of the relatively high complexity (low frequency) of vocabulary used. Concreteness and familiarity of topic have been shown to guide the type of vocabulary required to discuss it (McNamara 2013). The length of the original N-ER document also influenced the simplification process. Reducing a long text (such as 'Valuing People and Research' 5N) resulted in the removal of content which in turn limited the possibility for wider linguistic representations. In this case, intuitive simplification also resulted in an increase of repetitive cohesive cues evident for example, in the large number of noun overlaps of 'research' (5E) rather than the use of elaborated terms or synonyms as found in 5N. Redundancy here led to linguistic ambiguity and loss of meaning.

It can be argued that simplification of documents does require some sacrifice of content and style. However, the notable power differential identified in nearly all ER examples analysed was indicative of a pervasive change in tone (interpersonal function). A potentially problematic outcome is that this perpetuates recognised inequalities between

people with and without IDs in the discourse of ER documents which was not evident in the N-ER versions. In line with Butt et al.'s (2003) understanding of how relationships are represented in text through SFL, a comparatively high level of conditions imposed on the reader (as shown in 1E, 2E and 3E, the use of 'them' and 'they' rather than 'we' (1E and 2E) and the tendency to use directives and imperatives (1E and 4E) can serve to deepen this power differential.

Using more direct language (through increased cohesive cues and high frequency vocabulary) might be an unavoidable consequence of reducing ambiguity and confusion when communicating with people who have difficulties with receptive language. However, the resulting imposition of conditions combined with direct language and frequent use of terms of obligation had the additional effect of reducing the level of agency ascribed to the reader. This may be viewed as counterpoint to the drive towards social and political equality advocated by Disabled People's Organisations (e.g. People First, Opening Doors) and promoted by researchers and producers alike (Rogers and Namaganda 2005; Townsley 2015; Walmsley 2001; 2010; 2013).

Whilst the continued proliferation of ER material fulfils the legal duty for reasonable adjustment, its apparently low uptake by target groups challenges the economic question of supply-demand. Both Mander (2013) and Walmsley (2013) related that many people with IDs whom they spoke to were not aware of published ER material that was specific to their condition or situation. This raised the question of what purpose these particular ER documents served if they did not reach their identified population. As proposed by Wright (20013), careful understanding of the target audience through participation or consultation is key in helping to define what will be relevant to include in ER documents and how to write them. Reading abilities, attention and processing skills, prior knowledge of the topic, and reader goals should also be considered. However, conveying relevant information through a structurally simpler version of the N-ER document requires a deliberate technical approach to linguistic deconstruction and subsequent reconstruction. By paying more in-depth attention to the cohesive properties of language used and a

switch to elaboration rather than reduction in the choice of language, a more faithful version of the content of N-ER documents might be achieved. Furthermore, representations of increased equal power distribution evident in the N-ER versions could be maintained.

Some of the analysed texts displayed examples of simplification while maintaining equal ground on one or more functions: textual, representational and /or interpersonal . Despite the difficulties inherent in text simplification, the findings from this study highlight some areas for consideration. Firstly, the repetition of certain terms can constrain the construction of meaning and even confuse the reader. By using other cohesive devices, such as providing concrete examples when the topic is likely to be unfamiliar, or by elaborating and explaining ideas instead of reducing them, established processes are supported more easily by referents. This facilitates the task of making links or inferences. Secondly, the creation and perpetuation of power differentials can be seen as a counterpoint to the drive for reader empowerment. This trend may be reversed by using more carefully selected pronouns, by retaining modal constructions and by using vocabulary that imposes fewer constraints on choice and freedom. With more attention to linguistic detail this can be achieved while maintaining a direct, clear style of communication. Thirdly, better levels of coherence could be achieved by eliminating unnecessary reference to previous or future events unless these are pivotal to both the usefulness of the information itself and are evident in the N-ER version. Finally, the scope and interest of ER documents could be improved with more consideration of nuanced detail that expresses tone and attitude, and a commitment to producing a document that reflects the original version in style and emphasis. The question of whether it is possible to simplify language within ER documents while avoiding the creation of a strong power differential also needs to be addressed.

4.5.1 Limitations of Study C: Discourse Features

Although the texts included in this study were representative of DoH documents over a twelve year period, the sample analysed was small and the text segments were relatively short. Further similar analyses including a larger sample of text excerpts would support the pattern of interpretations discovered. Readability measures of ER material were used to select and identify five pairs of documents and aimed to select a range of material with differing sentence and word lengths. While selection related to the readability measures from ER documents, it did not consider the readability measures of N-ER documents in selection or alternative linguistic features which could have otherwise affected the discourse analysis.

Bullet points, headings, sub-headings and picture material were removed, but could arguably be relevant to how meaning might be conveyed and coherence constructed through the linguistic discourse of the text excerpts. While some structural devices were retained (e.g. paragraphs, inverted commas, question marks and exclamation marks), consideration of the possible impact on meaning construction from other structural devices was outside the scope of this study. Admittedly, the qualitative nature of the process of text analysis applied through SFL left it open to subjective interpretation. This was acknowledged and countered in this study insofar as all data was cross-checked between two analysts. Any differences in interpretations were resolved through consensus.

4.5.2 Conclusions and implications of Study C: Discourse Features

The critical differences noted in the ER material compared to their N-ER equivalents demonstrated specific reductions and representations in the information provided. The simplification process or shortening of text may be associated with an evident compromise on detail that had a consequential impact on cohesion. Whether reduced

detail as opposed to elaborated detail achieved improved understanding for readers of supported documents is not evidenced. A focus by authors on the presentational features of text such as morphosyntax whereby sentences are shortened, referents are repeated and verb constructions are simplified, could also negatively influence reader understanding in that the agency of a piece may be overlooked. Ultimately this runs the danger of further disempowering the reader.

ER documents should contain enough of the essence of the original (N-ER) version to provide necessary and sufficient relevant information in a manner that is coherent, as well as respectful of people with IDs as equal citizens. Increasing awareness of the impact of linguistic cohesion and representation on levels of understanding by the target audience, the relevance of the information and a consideration of author power could help to redress the apparent gaps in current models of ER DoH documentation.

4.5.3 From paper studies to a randomised experiment

Several important differences between the presentational and linguistic features in ER texts and those in N-ER versions have been identified in Studies A, B and C. Nonetheless, a skilled and careful rendition of a document in ER format incorporating cohesive structures that create explicit meaning, elaboration of concepts and the adjustment of aspects that reinforce power differentials, might still not be enough to accomplish full understanding for the reader. Beck et al. (1991) has demonstrated that constructing meaning from a text was the result of a complex interactive and cumulative task that defied the restraints of formulaic intervention. However, the question of how well ER documents in their current published form contribute to the construction of meaning in practice remains largely unanswered.

Comprehension of text is fundamentally underpinned by the language capacity of the reader. This is achieved through the use of literacy skills, including reading, cognitive abilities related to executive function (working memory, phonological memory, inhibition, flexibility) and attentional resources. Relevance theory (Sperber & Wilson 1996, 2002) proposed that within any interaction, human beings are programmed to seek out what is relevant to them using their internal capacities to interpret external signals (see p. 71). Explicit external signals in conjunction with adept internal capacities will probably lead to a more effective communication of information. The task of reading and understanding an ER document involves the interaction of these intrinsic factors (within the person) with those presented extrinsically (i.e. the nature of the ER document and any human mediating support). Consistent with Relevance Theory (Sperber and Wilson 1986), all of these factors contribute to the construction of relevance from any given communication event and are unique to every situation. Study D: The Easy Read Task, in Chapter 5 therefore investigated the effects of linguistic simplification and literacy mediation on the comprehension of ER text by people with intellectual disabilities through a randomised experiment.

Chapter 5. Study D: The Easy Read Task. The effects of linguistic simplification and mediation on the comprehension of 'Easy Read' text by people with intellectual disabilities: a randomised experiment.

The last three Studies A, B and C have examined presentational, linguistic and discourse aspects of paper-based ER documents and compared these to their N-ER comparators. The final Study D: The Easy Read Task completed The Easy Read Project. This study was an empirical investigation into the effect of simplified text and human mediation on the understanding of ER information by people with IDs. A brief background follows to contextualise Study D, and results are outlined and summarised. Limitations of The Easy Read Task have been considered at the end of this chapter. The main discussion of findings however, has been addressed in Chapter 6 where it has been more fully reviewed, taking into account findings from Studies A, B and C.

5.1 Background to The Easy Read Task

As revealed in Studies A, B and C, ER material differed from its N-ER DoH comparators on presentational, linguistic and discourse features. ER material was characterised by surface level changes to layout, the use of simple language structures, shorter words and sentences and picture material (Study A: The Survey; p. 105). Other features such as high frequency, concrete, imageable words were found to be more commonly used in ER material and these primarily contributed to low lexical variation and reduced vocabulary (Study B: Linguistic Analysis; p. 138). It was also shown that less attention had been given to how meaning was constructed through the patterns of cohesive devices used in ER documents. In Study C: Discourse Features; p. 158) repetition (co-reference) and limits on the vocabulary in ER material led to discourse that was likely to be more difficult to understand than the discourse patterns found in N-ER material. This was due in part to the reduction in content and the way that repetition interfered with overall coherence. There were also a number of aspects revealed in the ER material that may have negatively

affected power equality in the interaction between text and person (Study C: Discourse Features; p. 162).

These three paper-based studies demonstrated the effects of adaptation and language simplification on written DoH documents when transformed from N-ER to ER format. Nevertheless, questions remained about whether ER material such as that published by the DoH could positively influence the way information was understood in practice by readers with IDs.

Reading ability as part of the reader's intrinsic skill set has been identified as one of the most obvious factors that could affect how well ER material is understood in practice. As evidenced in the Introduction (p.60 - 62), language capacity, executive function, specifically working memory, have been shown to underpin successful efficient reading processes. Nash & Heath (2011) and van Wingerden et al. (2014) showed that reading comprehension was affected particularly by vocabulary knowledge and this was a main predictor of reading comprehension in adult learners with IDs. Notwithstanding, there is likely to be variability within this relationship because of the marked heterogeneity of the population with IDs, with some individuals being proficient readers and others unable to read at all.

Papen (2009) has suggested that literacy mediation can act as an extrinsic factor to overcome barriers to understanding complex concepts, especially related to information about health. She demonstrated how dialogue reduced the variability of interpretation within health consultations. Connected to the idea of clarification of information, McNamara (2013) demonstrated that recent personal experience of a text topic by the reader was associated with quicker activation of knowledge, resulting in more linking of information (inferences) and improved understanding of a text. This activation process was known as creating a 'situation model' in CI theories of reading for comprehension (McNamara and Magliano, 2009). Being able to construct a 'situation model' is a crucial

factor in the process of making sense of written text. Dialogue through mediation in place of personal experience was also demonstrated by van Lehn et al. (2007) to be effective in improving the comprehension of written material for children learning to read. Interactive discussion about the texts helped to create links and facilitated the activation of prior knowledge. A number of interactive techniques and strategies have been used with people with IDs as mediating support for understanding written information (see p.66). Two of the studies most relevant to The Easy Read Task are outlined below.

Reciprocal reading methods (Palinscar and Brown 1984) were used successfully to develop text understanding by Alfassi et al. (2009) with readers with IDs. This process was originally devised by Palinscar & Brown (1984) who implemented a prescribed discussion process (see Materials and procedure p. 181) in educational contexts with readers who experienced difficulties with comprehension of texts. Alfassi et al. (2009) focused less on the reader's individual literacy interests and created a structured dialogue about a shared text using a process of summary, clarification, and the joint formulation of questions with thirty-five participants. They found that reading comprehension significantly improved in the condition where reciprocal reading was implemented. Mander (2013) investigated the role of mediation in four one-to-one interactions between community nurses who used ER material with their clients with IDs. She analysed her observations using a CA approach. The ER material was useful in establishing joint attention. However, she gave more prominence to the level, choice and accuracy of the *language* used by the mediators and their ability to relate new information to the client's personal experience. Although the ER documents functioned as one corner of her 'triangle of accessible information' model (see p. 69), they did not feature centrally in the analysis of interactions. Furthermore, there was little evidence that the process of conveying information through conversation with the support of an ER document improved depth of knowledge or facilitated conceptual understanding such that it could be acted upon later. This raised questions concerning what constitutes effective mediation for people with IDs when using ER documents and what function the ER document plays within those interactions.

The purpose of Study D: The Easy Read Task was to investigate the effect of intrinsic and extrinsic factors on the reading comprehension of ER material. The research questions were: How do adults with IDs understand health-related ER information when 1. extrinsic factors (i) linguistic complexity, and (ii) literacy mediation are included, and when 2. intrinsic factors, (i) receptive vocabulary, and (ii) reading comprehension are taken into account? Adults with IDs were recruited and randomised into one of four different groups where they were asked to read either 'linguistically complex' or 'linguistically simple' text with or without receiving 'mediation'. It was hypothesised that if 'standard' ER texts (simplified linguistically in accordance with conventional guidelines and with similar face validity as described in Studies A, B and C) were fulfilling their stated intentions, readers who used them and who also had the benefit of mediation would score more highly on a measure of comprehension than readers using linguistically complex text who were given no mediation.

However the findings from Studies A, B and C that focused on a comparison of ER and N-ER texts led to the suggestion of an alternative hypothesis. This initial study focused on 'typical' ER material and was designed as a pilot to provide baseline data for future experiments where certain features could be systematically manipulated and tested. As found in Study A: Survey, and Study B: Linguistic Analysis, ER documents were composed of different surface level features compared to N-ER material such as the addition of picture material, the use of large font and linguistic simplification through the use of shorter sentences and more familiar, high frequency, concrete vocabulary. Both Study B: Linguistic Analysis and Study C: Discourse Analysis confirmed that typically, the use of simplified language of the kind found in ER documents also resulted in reduced lexical variation, increased repetition and increased similarity of syntactic structures. The interaction of these outcomes had the effect of creating ER texts that relied on repetition rather than on elaboration of ideas and were therefore less cohesive in terms of providing meaningful information. It could therefore be hypothesised that when faced with typically simplified ER texts with reduced lexical variation and increased repetition, readers would *not* score more highly on measures of comprehension. Based on positive findings resulting from literacy mediation (Papen, 2009; Alfassi et al., 2009), it was also

hypothesised that standardised mediation would help to increase the comprehension measure.

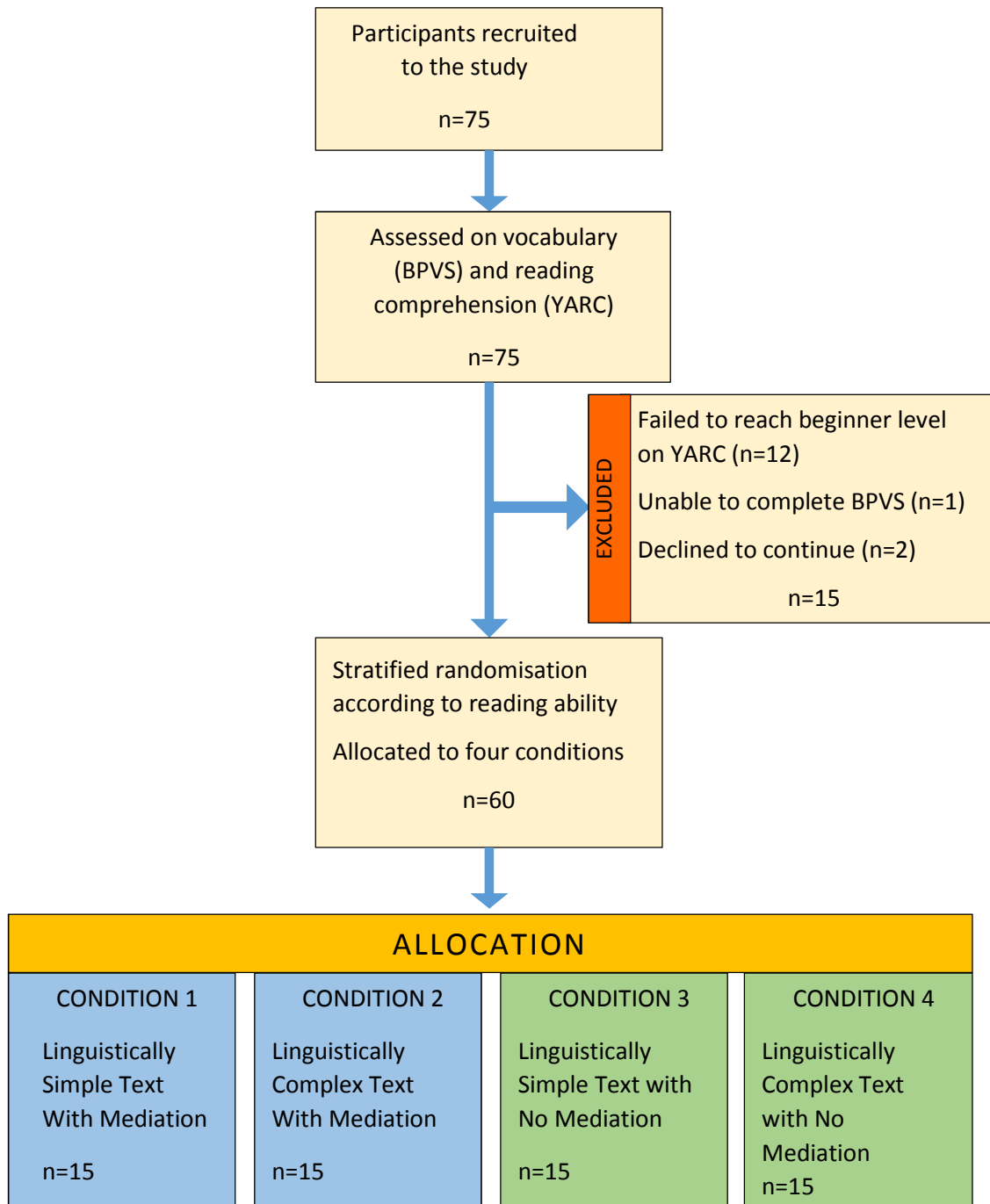
5.2 The Easy Read Task method

Participants

Seventy-five adult participants with IDs (Mean age = 38 years, 9 months; SD = 16 years, 1 month; 43% men) were recruited. Seventy-four participants were of white British ethnicity, and one participant self-identified as British Asian.

The initial inclusion criteria were 1) aged between 16 and 75, and 2) self-identified as having IDs. In order to ensure that participants had IDs, they were recruited from services specifically established for people with IDs. The exclusion criteria were, 1. difficulties with hearing and language skills which prevented one to one conversation in a familiar environment, and 2. unable to see font size 18 for reading. Further inclusion criteria were applied after initial assessment measures were taken. These were 3. able to complete a receptive vocabulary assessment (The British Picture Vocabulary Scales (BPVS II), Dunn et al., 1997) and 4. able to read 'Beginner Level' text (York Assessment of Reading Comprehension (YARC) 2nd edition, Snowling et al., 2011). Fifteen participants were excluded at the initial assessment stage or early in The Easy Read Task. Twelve of these did not reach 'Beginner Level' reading on assessment, one was unable to continue with the vocabulary assessment, and two declined to continue after the reading assessment. A total of sixty participants were finally included in the study. This process is shown in the Consort diagram in Figure 5.2.1 below.

Figure 5.2.1 The Easy Read Task recruitment and allocation process



Power calculation

A power calculation was made from estimates based on reading comprehension outcomes from two pilot trials of The Easy Read Task. It was predicted that the mean score for each group would be: Group 1 = 20.4, Group 2 = 16.8, Group 3 = 16.8, and

Group 4 = 9.0, with a standard deviation of 7.5. Parametric ANOVA was considered likely to be used for the analysis. This data resulted in an effect size of $f = .56$; setting the significance level at 0.05, with power set to 0.80 which resulted in an estimated sample size of ten participants per group, or a total sample size of forty. Following data collection from forty people, findings were not showing expected outcomes. There was a very close to significant interaction between 2 variables (simple text and mediation) and it was decided that in order to clarify this interaction, the sample should be extended. Approval was granted from the NHS Ethics Committee for a substantial change to the study design and a further twenty participants were recruited to strengthen data.

Design

A 2 x 2 randomised experimental between subjects design was used. The factors were A) linguistic simplicity: 1) simple or 2) complex, and B) mediation: 1) present or 2) absent. The study was carried out in six urban and semi-rural community settings in the east of England with adults with IDs who self-identified as 'readers'.

Ethics and recruitment

Following a favourable ethical opinion from the NRES Committee, East Midlands – Northampton (REF 13/EM/0474) (Appendix Chapter 5. i Ethical approval), gatekeepers (day centre managers or advocacy group leaders) at six community locations were contacted and provided with information about the project. Ethical issues of participant confidentiality, the possibility of coercion, ensuring mental capacity of participants, the pressures of feeling assessed, fatigue and expectations of remuneration were each considered and precautions identified at the stage of making an application to NRES. These can be found in more detail in Appendix Chapter 5. ii Ethical considerations.

ER publicity leaflets (Appendix Chapter 5. iii Publicity leaflets) were distributed by gatekeepers, who generated a list of potential participants based on service user knowledge and in consultation with support staff and/or key workers. Gatekeepers

explained the process to potential participants, using an ER information sheet (Appendix Chapter 5. iv Information sheet 1) to ascertain interest. N-ER information sheets without picture support were also available for carers, family members, staff and participants that expressed a preference for these (Appendix Chapter 5. iv Information sheet 2). Both information sheets contained the same information. The name of anyone who had declined to participate was recorded and the person was not approached again unless they initiated interest in taking part.

On three occasions, gatekeepers demonstrated reluctance to allow the researcher to talk directly to the adults in their day centre groups. One reported that no group members wished to participate because none of them were familiar with ER material. One maintained that none of the ten people in their citizenship group was able to read at beginner level and that the consent form was too complicated and difficult to understand, and the third reported that everyone in their group could read very well and didn't need to use ER material. On these occasions, the researcher asked to be put in contact with other gatekeepers who might be interested within the same organisations. A number of people who had previously not been considered, were then recruited through different activity groups which they also attended. On average, one third of all the adults who attended sessions where the researcher explained about The Easy Read Project were willing to take part.

An ER consent form (Appendix 5 v. Consent form) supported by the information sheet was used by the researcher to gain informed signed consent. All ER documentation including publicity leaflets, information sheets and consent forms were produced in collaboration with a local group of volunteers from The Opening Doors Advocacy Group in Norfolk. This process is explained in more detail below under Materials and Procedure. Consent forms and information sheets scored between Grade 4 and 5 on the Flesch-Kincaid Readability Measure through Coh-Metrix (Graesser et al., 2011). Participant anonymity was maintained through the use of coding on data collection sheets that were stored separately to any identifying documentation. Personal information was securely

stored and only the principal researcher had access to this. Participants were able to withdraw from the project at any time without giving a reason. Data were collected over a six month period.

Details about behaviours or physical difficulties (e.g. vision or hearing) that required support or that could impact on communication or reading were collected once informed consent had been given by a participant (Appendix Chapter 5. vi Participant recruitment profile). A rating of language, literacy and communication abilities was completed by the gatekeeper or the researcher to determine whether the criterion for communication skills and the ability to hold a basic one to one conversation was met. Adapted from the Aphasia Severity Rating Scale in the Boston Diagnostic Aphasia Examination (Goodglass et al., 2001), the rating scale ranged from 1: 'no usable speech or verbal comprehension' to 6: 'minimal discernible communication difficulties; individual may have subjective difficulties, which are apparent to the listener'. Individual communication scale ratings for recruited participants ranged from 2-6, $M = 5.47$ ($SD = 0.89$).

Initial assessments

All participants who met the initial inclusion criteria completed an assessment of receptive vocabulary (BPVS II, Dunn et al., 1997) and reading comprehension (YARC, Snowling et al., 2011).

The BPVS II (Dunn et al., 1997) provided an indication of the surface level understanding of spoken vocabulary. It has been standardised on a UK population of children and young people from three to fifteen years of age. For each item, the participant was shown four black and white line drawings and was asked to point to the picture that matched one spoken word given by the researcher. The test was discontinued after eight contiguous items were incorrectly identified. This assessment provided relevant information on participants' receptive vocabulary levels. Standardised scores, percentile ranks and age equivalent scores were calculated.

The YARC (Snowling et al., 2011) was used in the absence of any available standardised reading assessment that measured emerging reading skills for an adult population. The YARC was developed to assess abilities at and below Year One and up to Year Six of the Primary National Strategy in the UK. The assessment has been standardised on over 1000 children between the ages of five and twelve across the UK; (3.9 percent of the standardised sample are identified as having a statement of special educational needs). The 'Passage Reading Assessments' section was used. Reading passages were chosen based on the reader's preliminary performance on the YARC Single Word Reading Test (SWRT). The 'Basic Level' reading passage involved a shared reading task of three sentences and passages of increasing complexity were used according to the reader's level of ability. Any testing was discontinued if the reader made more than fifteen reading errors. Participants were asked to read two passages aloud and to answer a series of eight open questions about what they had read. Standardised scores and age equivalents were calculated for reading comprehension.

Randomisation

Sixty participants were then randomly assigned to conditions using permuted-block sizes of four, stratified according to reading abilities, in order to ensure that groups were well matched. The four conditions were: 1) Linguistically Simple Text with Mediation, 2) Linguistically Complex Text with Mediation, 3) Linguistically Simple Text with No Mediation, and 4) Linguistically Complex Text with No Mediation.

Materials and procedure

All 'easy-read' documents used in the study, including The Easy Read Task texts were developed during a three-month collaboration through co-production workshops with the Opening Doors Advocacy Group, Norfolk. The style of presentation closely followed advice given by a committee of five volunteers about picture use, format, font and style. The researcher presented the group with a range of printed options with a variety of fonts, layouts and picture material. Through a process of elimination of different

presentational and linguistic features, consensus was reached about the format of the final documents. Information and consent forms subsequently required some amendments due to requirement from the NHS Ethics Committee. Two members of the group further supported the development of material by taking part in a pilot run of The Easy Read Task.

The final text content for The Easy Read Task was based on information about food and keeping healthy taken from 'You and Your Health' (MENCAP 2003) and 'Healthy Lives Healthy People' (DoH, 2011). 'Healthy eating' is topical within primary healthcare and provided a theme for the task material that was familiar to a wide range of possible participants, and therefore was thought to have the potential to increase motivation for reading and understanding (Morgan & Moni 2008).

Two reading texts were created to replicate text excerpts taken from two DoH ER documents available on the internet. Random selection of excerpts out of thirty-five documents followed the same procedure carried out for the selection of text excerpts in Study A: The Survey, prior to running readability measures (p. 86). The ER excerpt with the highest Flesch-Kincaid readability score (Flesch 1948) and also the one with the lowest score were identified as models for the preparation of linguistically simple and linguistically complex texts respectively for The Easy Read Task. Both text excerpts were between two hundred and sixty and two hundred and eighty words in length.

The Linguistically Simple and Complex Texts for The Easy Read Task (Appendix Chapter 5. ix Text A and Appendix Chapter 5. x Text B) were produced with coloured pictures and symbols taken from Clipart and Google images, thus creating documents similar to those produced by the DoH. Pictures were included to create documents that resembled currently available ER documents as closely as possible. This was to ensure face validity by creating material that was credible as ER to the participants. Internet sources were used to provide as wide a scope as possible for choosing pictures that related to the text.

Moreover, using images that were freely available avoided any focus on one particular type of marketed product. Both Simple and Complex texts were matched in format, font size and type, and the number of pages used. Bullet points were implemented for lists of words in both texts (again to comply with face validity), and similar content in texts was supported with the same picture material as far as possible.

The designed texts were scored for readability and on TERA (Text Ease and Readability Assessor) profiles. TERA is a tool created by the Coh-Metrix team as an educational measure. It provides a compressed version of the automated linguistic measures available in Coh-Metrix (Graesser et al., 2011) and covers the same five areas: narrativity, syntactic simplicity, word concreteness, referential cohesion and deep cohesion (McNamara et al., 2011). Profiles show how the Linguistically Complex and Simple Texts for The Easy Read Task differed across aspects.

The Easy Read Task texts were compared against the TERA measures taken from the model DoH excerpts. Language was manipulated to achieve a match as close as possible to the models. TERA profiles can be seen below in Figures 5.2.2 and 5.2.3.

Figure 5.2.2 TERA measures for The Linguistically Simple Text

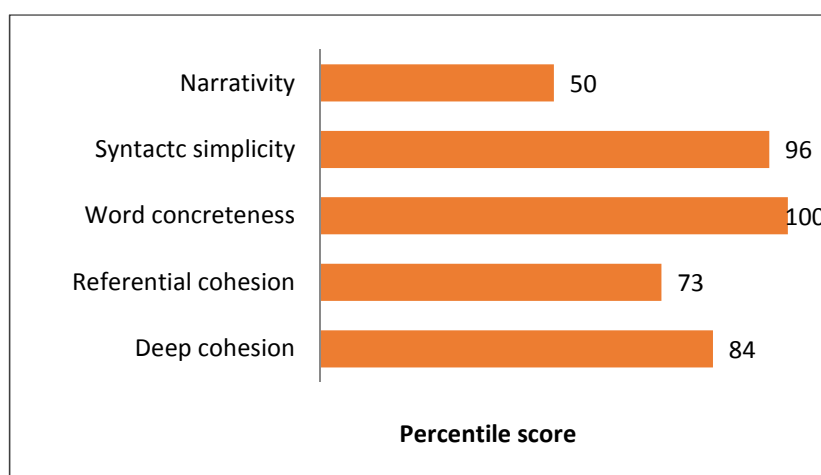
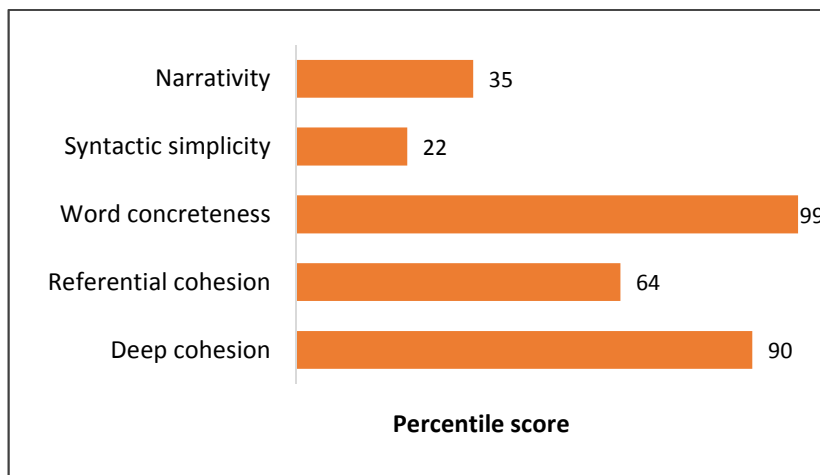


Figure 5.2.3 TERA measures for The Linguistically Complex Text



The Linguistically Simple Text resulted in a Flesch Kincaid Grade Level of 4 ('easy' to read), with a TERA profile that showed a higher percentile score on syntactic simplicity and a relatively high score on narrativity. The Linguistically Complex Text by comparison measured Grade Level 14 on Flesch Kincaid Readability and was syntactically more complex with less narrative construction. There were fewer differences on word concreteness, or cohesion measures between the two texts. These profiles represented the patterns of linguistic simplification revealed in DoH ER documents in Study B: Linguistic Analysis where surface level modifications that related to simpler syntax seemed to indicate a high incidence of cohesive devices. Closer examination of these patterns in Study C: Discourse Features, revealed that the prominent cohesive device (repetition) found in ER material in fact led to reduced coherence. The patterns of linguistic simplification and discourse were retained in The Easy Read Task to replicate current ER material as closely as possible.

The Easy Read Task.

Specifically designed for this study, The Easy Read Task was used to measure reading comprehension of linguistically complex and simple ER material with and without mediation. Eight questions were formulated to tap superficial recall, deep recall and the inferential application of information from within the text, based on the YARC (Snowling

et al., 2011) model for assessing reading comprehension. Definitions of the reading comprehension levels adapted from Snowling et al. (2011) for this study can be found in Appendix Chapter 5. Vii. As far as possible, questions for Simple and Complex texts retained the same wording.

Table 5.2.1 The Easy Read Task questions

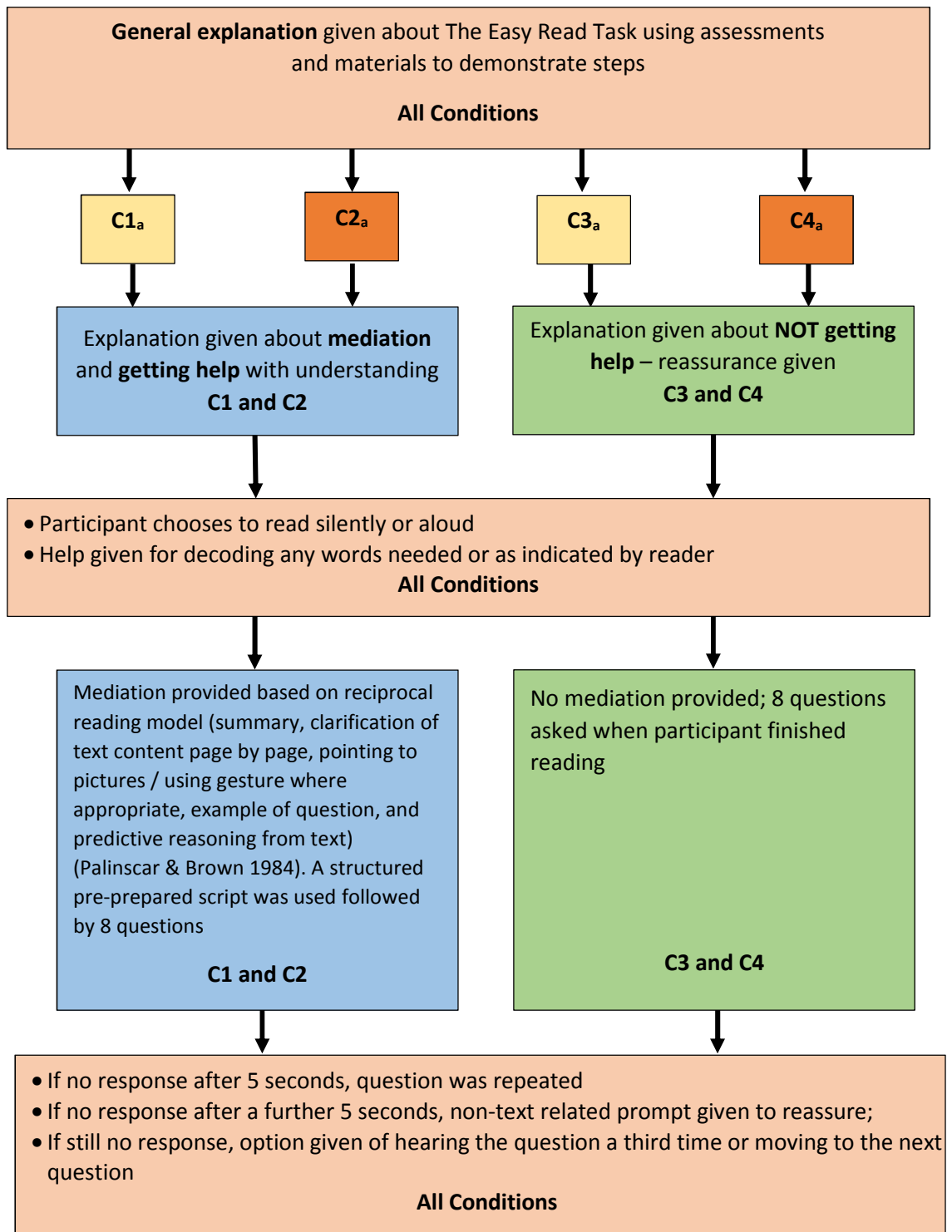
	Classification (YARC, Snowling et al., 2011)	Question	Asked with linguistically Simple or Complex Text
1	Literal	What foods give you energy? What foods give you good carbohydrates?	Simple Complex
2	Vocabulary dependent	What does fibre in your food do?	Simple and Complex
3	Coherence inference: linguistic	What helps you get vitamins?	Simple and Complex
4	Coherence inference: knowledge based	What foods are not very good for you?	Simple and Complex
5	Elaborative inference	What would happen if you stuck to the 5- fruit and vegetables-a-day rule?	Simple and Complex
6	Evaluative inference	How would you feel if you ate a lot of sugar? How would it feel if you ate a lot of fat and salt?	Simple Complex
7	Logical/deductive reasoning	If you had a friend with a bad heart, what advice about food would you give him?	Simple and Complex
8		Someone you know has broken her arm. What are the best foods for her to eat?	Simple and Complex

Questions are displayed in Table 5.2.1 above. Only Question 1. (literal) and Question 6. (inferential) differed in the vocabulary used between Simple and Complex conditions. This ensured that the requirements of the questions could be specifically fulfilled by an answer closely related to the text content (Question 1) or inferred from the text (Question 6). Syntactic construction was maintained across all questions in both texts. For each participant, question numbers 1-8 were delivered in the same order.

Depending on the condition allocated to each participant, procedure was followed as indicated below in the consort diagram in Figure 5.2.4. Explanations were given to

participants about the process prior to the task. ER support sheets were available to support understanding (Appendix Chapter 5. xii ER Support sheets).

Figure 5.2.4 Procedure for The Easy Read Task



a = Condition 1 = Simple Text with Mediation, Condition 2 = Complex Text with Mediation, Condition 3 = Simple Text with No Mediation, Condition 4 = Complex Text with No Mediation

All participants were given the option of reading aloud or silently. Mediation based on a model of Reciprocal Reading (Palinscar and Brown 1984) was delivered to participants in Conditions 1 and 3. The four main strategies used: summary, clarification, generating questions and prediction are shown in Table 5.2.2. All participants were given the option of reading aloud or silently. Decoding support as understood within The Simple View of Reading (p. 53 - 54) was also given to all participants. This involved supporting participants to recognise letters and decode them into English words, and was separate from the linguistic knowledge of and about words that was then activated by readers for constructing meaning.

Table 5.2.2 Reciprocal reading definitions and steps

Support	Definition	Example
Summary	A brief summary of the main idea within the text. Can be a short sentence reflecting the core message	'This text is about what to eat and what not to eat if you want to stay healthy.'
Question	A question that the text answers and that reflects the main idea of the text. (Should avoid introducing questions at this point that are directly asked as part of the task)	'The information here would help you answer a question like...What do you need to eat if you want to stay healthy?'
Clarification	Clarification of the text, in chunks, explaining the information, using gesture, pointing to pictures as appropriate. Specific examples from the text can be used. No further elaboration necessary. Responses to requests for clarification of specific information can be made at this stage.	'Now we can look at it together and I'm going to explain the information in case there are things that you do not understand.' 'Here it talks about protein. That is something in food that helps our bodies. It helps our bodies to grow and also to get better... It says here that you can eat foods with protein like cheese and meat. They will help your body to mend itself or get better.'
Prediction	Provides reader with further elaboration about the text to help with inferential application of information.	'So for example, if I cut my finger, it might help to get better more quickly if I ate some protein. I could eat some meat or cheese.'

(Adapted from Palinscar and Brown 1986)

Pre-prepared scripts were used to guide the mediation process to maintain equity across delivery of mediation to allocated participants. The script for mediation used with participants who received Text A can be seen in Figure 5.2.3 below. A similar script devised for use with participants who received mediation with Text B can be found in Appendix Chapter 5. xiii Mediation scripts.

Table 5.2.3 Script to guide mediation with Text A

Mediation Text A	Script
Summary	This is about what to eat and what not to eat if you want to stay healthy.
Clarification of each section in text	<ul style="list-style-type: none"> • Here it tells us that we need food and water for 2 things – to grow and to be healthy. • It talks about fruit and vegetables – and about eating 5-a-day. This helps us get vitamins • Then it gives some examples of things you can eat to get your 5-a-day like apples, bananas, oranges, or peas, carrots and broccoli. • This section talks about energy foods. They call them carbohydrates. It gives some examples like bread and potatoes and pasta. • We also need fibre in our diet. This shows that fibre can help you to go to the toilet. There are some examples here of good food with fibre like brown bread, brown rice, fruit, vegetables, breakfast cereal and porridge. • Then there are foods that help your body to recover or to get well. It says here that these are called proteins. Like meat, chicken, fish, lentils... • And foods like cheese, milk and yogurt are good for getting calcium for your bones. Also it helps your teeth. It's good to eat something with calcium every day. • Finally here, it talks about foods that are not so good for you. These are things with lots of sugar and fat. Too much of these foods can make your teeth bad and make you put on weight. Also for your heart, it's not good to eat too much salt and fat like too many chips or crisps.
Example of a possible question that might be asked	So for example, you could ask someone a question about this information, like 'What kind of food is bad for your teeth?' or 'What makes Weetabix and porridge good for you?'
Prediction/ inference about information given in the text	I suppose if I saw some of my friends eating chips every day, I might worry about them putting on a lot of weight or having heart problems. I might try and help them to stop eating chips every day.

The mediator pointed to relevant pictures and words in the text while providing explanation and allowed pauses for participant initiation. Any question, comment or query initiated by the participants was responded to. Participant responses were scored according to the semantic closeness of the answer to a defined target answer and recorded in pre-prepared record sheets (see Appendix Chapter 5. xi Record sheets).

Table 5.2.4 Example of scoring guide for Question 1, Linguistically Complex Text

Question 1 What foods give you good carbohydrates? (Literal)

DEFINITION	ELABORATION	EXAMPLE	SCORE
Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	(Wholewheat/ brown) bread, cereals (or named), brown rice (one or more of the above =3) BUT reduce to 2 points if too many other foods are also named (ie. if maxim of quantity is flouted see example).	3
Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	Fruit and OR veg (apple, orange, broccoli, carrots)/ 5-a-day/ milk, yogurt, cheese/	2
Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Drink a lot of water/ Lots of different food/ foods with calcium/ protein/ fat/ sugar/ salt/ good for bones and teeth	1
No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	Harry Potter /I eat at the HUB/ Sainsbury's/ chocolate / cakes/ butter/ chips	0
No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it	0

A detailed scoring guide was developed for each question with definitions, elaborated information and examples for every score (0-3), where 0 = response with no semantic relation and 3 = response with precise semantic relation to the content or context of the target answer. An example of the scoring guide from Question 1 for the Complex Text is provided in Table 5.2.2 above.

Full scoring guides with elaborations and examples for each question related to the Simple Text and the Complex Text can be found in Appendix Chapter 5. ix and Appendix Chapter 5. x Linguistically Simple / Complex Texts, questions and scoring guides.

A final total score out of a possible twenty-eight was calculated for each participant. The full data collection process did not take longer than one hour and thirty minutes for any contact. Fifty-five participants completed the two preliminary assessments and The Easy Read Task in one visit and five required one further visit.

Data preparation

Reliability

Inter-rater reliability was calculated using all answers from one third of participants (n=20) which were scored independently by a colleague as second scorer. Participants for inclusion in the reliability study were randomly selected using an online electronic randomiser (Research Randomizer).

For training purposes, prior to second rater scoring, six sets of dummy data were prepared; three with questions relating to the Complex text and three relating to the Simple text. These were previously scored by the researcher and results were not shown to the second scorer. After explaining the principles of scoring using relevant material, the researcher demonstrated scoring of the first set of data using full scoring guides to indicate how to score each question (See Appendix Chapter 5. ix and 5. x). The second and third examples were scored independently by the second scorer and outcomes were compared. Discrepancies at the training level were resolved through discussion and close

reference to the scoring guides. Independent scoring was then carried out with real data and discrepancies resolved through consensus. Inter-rater reliability was found to be, $k = 0.71$, indicating good to substantial agreement (Fleiss 1981 in Pring, 2005: 207).

Analysis

Data from all three measures (BPVS, YARC and The Easy Read Task) were entered into a database and analysed using SPSS Version 22 (IBM 2013). Testing was carried out for matching across conditions on age, gender, the communication scale rating, vocabulary (BPVS) and reading comprehension (YARC) and means are shown in Table 5.3.1 below.

Levene's test showed normal distribution of data for participant age ($p > 0.05$). ANOVA demonstrated no significant difference between the four conditions $F(3, 56) = .511, p = .676$. To test for variance across the groups on the communication scale (a six-point subjective rating), the Kruskal-Wallis Test for non-parametric data was applied. Again, no significant difference was found between conditions $H(3) = .318, p = .957$. The distribution of gender across groups was evaluated using a Chi square test and no significant differences were found, $X^2(3) = 5.7, p = .127$.

Also using ANOVA, there was no significant difference between the four groups on mean vocabulary levels (BPVS), $F(3, 56) = .465, p = .708$, or reading comprehension scores (YARC), $F(3, 56) = 1.38, p = .260$. Levene's test for homogeneity of variance was non-significant ($p > 0.05$) for both tests, hence assumptions were not violated.

A two-way ANOVA was initially completed to measure main effects of linguistic complexity and support on The Easy Read score, followed by ANCOVA with the inclusion of two covariates: reading comprehension and receptive vocabulary scores, both of which were anticipated to affect performance. The assumption of homogeneity of regression slopes was not violated for either receptive vocabulary, $F(1, 53) = 3.34, p = .073$, or

reading comprehension, $F(1, 53) = <1, p = .638$, thus indicating that the assumptions governing the use of ANCOVA were not violated. Data were inspected for substantial departures from normality, and data associated with Condition 3 (Linguistically Simple with No Mediation) was found to be non-normal. Attempts to transform the data were unsuccessful. Therefore, nonparametric bootstrapping using 5000 samples with replacement was used to calculate both the p -value and bias corrected and accelerated confidence intervals around the parameter estimate. The p -value and confidence intervals reported throughout were calculated using bootstrapping. Nonparametric bootstrapping provides an estimate of the sampling distribution that is based on an original sample, and is appropriate to use if the original sample is representative of the population being studied (Efron & Tibshirani, 1993). Posthoc testing was undertaken using the Sidak method.

5.3 The Easy Read Task results

Table 5.3.1 Comparison of characteristics, baseline measures and The Easy Read Task scores across conditions

	Condition 1 _a	Condition 2 _a	Condition 3 _a	Condition 4 _a	p
Background Characteristics					
Gender					
Male	n = 3 (20%)	n = 8 (53%)	n = 6 (40%)	n = 9 (60%)	.127
Female	n =12 (80%)	n = 7 (47%)	n = 9 (60%)	n = 6 (40%)	
	M (SD)	M (SD)	M (SD)	M (SD)	
Age (years; months)	39;03 (15)	43;08 (17;08)	38;05 (20;02)	36;01 (14;06)	.676
Communication scale	5.47 (.91)	5.4 (1)	5.53 (.52)	5.47 (1)	.957
Language and Reading Pre-Test Variables					
Vocabulary (BPVS) _b	113.07 (35.75)	118.60 (44.95)	102.60 (39.21)	115.07 (35.59)	.708
Reading Comprehension(YARC) _b	113.07 (35.75)	118.60 (44.95)	102.60 (39.21)	102.60 (39.21)	.260
Dependent Variable					
Easy Read Task score (possible 28)	16.8 (4.43)	12.87 (5.17)	14.13 (5.18)	14.73 (5.05)	.245

a = Condition 1 = Simple Text with Mediation, Condition 2 = Complex Text with Mediation, Condition 3 = Simple Text with No Mediation, Condition 4 = Complex Text with No Mediation; b = Scores given in months as used in data analysis

ANOVA

As expected, collapsing across Linguistic Complexity, reading comprehension on The Easy Read Task did not differ significantly between those who were randomised to receive Mediation or No Mediation, $F(1, 57) = < 1, p = .770, 95\% BC_a CI [-3.06, 2.17]$. Collapsing across Mediation, reading comprehension on The Easy Read Task also did not differ significantly between those who were randomised to either the Linguistically Complex or Simple Text, $F(1, 57) = 1.63, p = .213, 95\%, BC_a CI [-.98, 4.32]$. There was no significant interaction between Linguistic Complexity or Mediation, $F(1, 57) = 3.12, p = .084, 95\% BC_a CI [-9.50, 0.50]$.

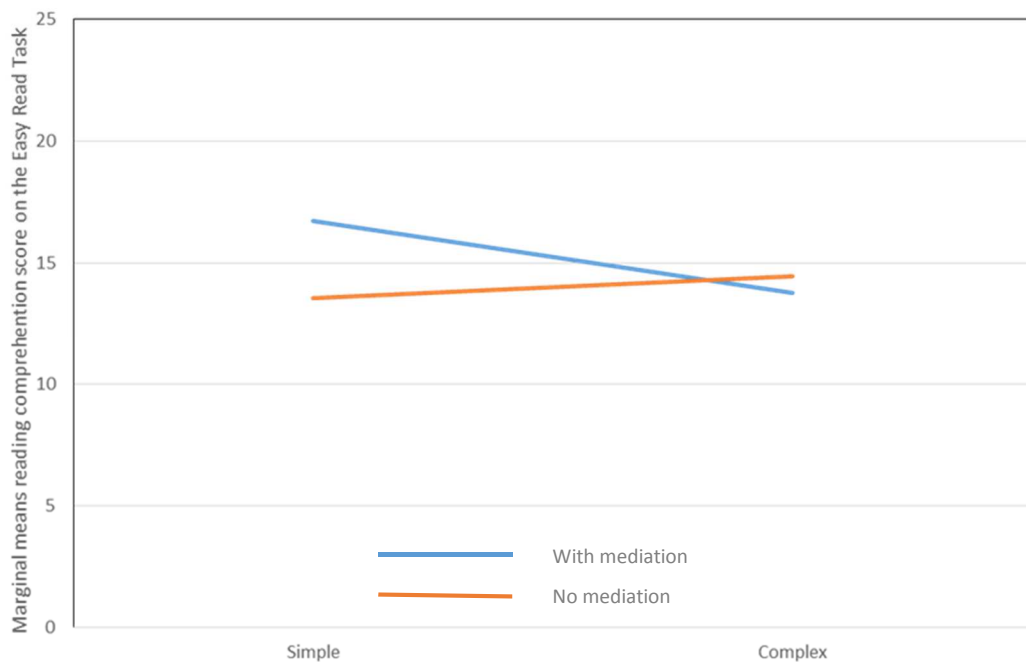
Pearson's correlation co-efficient showed there was a significant positive correlation between both receptive vocabulary, $r(60) = .686, p < .001$ and The Easy Read Task scores and reading comprehension $r(60) = .579, p < .001$ and The Easy Read Task scores. These covariates were included in the following ANCOVA.

ANCOVA

Controlling for receptive vocabulary (BPVS II scores), there was no difference in The Easy Read Task scores on comprehension for those randomised to either the Linguistically Complex or Simple Text, $F(1, 57) = 1.18, p = .277, 95\% BC_a CI [-.84, 2.9]$, nor for those randomised to receive either Mediation or No Mediation, $F(1, 57) = 1.71, p = .186, 95\% BC_a CI [-3.11, 0.72]$.

However, there was a significant interaction between factors Linguistic Complexity and Mediation when controlling for receptive vocabulary $F(1, 57) = 4.64, p = .039, 95\% BC_a CI [-7.42, -3.69]$ (see Figure 5.2.5). Posthoc testing revealed that the group who received the 'Simple Text with Mediation' performed significantly better on The Easy Read Task than the group that had the 'Complex Text with Mediation', $p = .011$. None of the other differences between the remaining groups were significant, $p > .05$.

Figure 5.3.1 Interaction between factors: linguistically simple text and mediation



When reading comprehension (YARC) ability was controlled, no significant main effect for Linguistic Complexity, $F(1, 57) = 1.28, p = .265, 95\% BC_a CI [- .98, 3.38]$, or Mediaton, $F(1, 57) = < 1, p = .400, 95\% BC_a CI [- 3.22, 1.27]$, was found. The interaction between Linguistic Complexity and Mediation was also not significant. $F(1, 57) = < 1, p = .371, 95\% BC_a CI [- 6.54, 2.26]$.

5.4 The Easy Read Task results summary

Based on findings relating to the lack of cohesion in ER texts (Studies A, B and C), it was hypothesised that participants who read the Linguistically Simple Text would not score more highly on the reading comprehension measure than those who read the Linguistically Complex Text. However, it was anticipated that participants who received mediation would achieve a higher comprehension score. As expected, findings did support the first hypothesis: that linguistic simplification had no significant effect on participants' understanding of information. However, neither linguistic complexity of text *nor* mediation was associated with significant gains in participant understanding of

information. Comprehension performance on the Easy Read Task questions did correlate significantly with both receptive vocabulary and reading comprehension, indicating that there was an association between these factors, and the ability to understand either of the ER texts more effectively in this study. While controlling for reading comprehension ability within the analysis did not alter the findings, controlling for receptive vocabulary revealed that those who received the Linguistically Simple Text with Mediation performed significantly better than those who received the Linguistically *Complex* Text with Mediation. Thus some of the variability in scores could be attributed to receptive vocabulary ability, and controlling for this within the analysis, indicated that Linguistically Simple Text with Mediation may be the most helpful for readers with IDs.

5.4.1 Limitations of Study D: The Easy Read Task

Study D made use of a community-based sample of readers with IDs, and as such, this sample was likely representative of the wider community that falls into this category. Although recruitment included participants with emerging reading skills, this could have excluded a number of 'non-readers' with IDs who use wider literacy or language abilities to understand ER material in everyday life with or without mediation.

The potential for confounding results due to variability in reading and language skills was ruled out by strict adherence to the randomisation of participants to conditions according to their reading ability. There was a good equivalence of individual skill set (intrinsic factors) across the groups. Situational and contextual factors such as fatigue, hunger, distractions in the immediate environment, anxiety due to impending activity changes or any other factors affecting participants' emotional and physical states could have influenced their performance on The Easy Read Task.

Use of an experimental design allowed for some conclusions about causality although questions remain in terms of the variable influence of factors other than reading and language on individual interactions. For example, speed and accuracy of reading are closely aligned to successful decoding of printed matter. The focus in The Easy Read Task was on reading comprehension, and while decoding skills might have impacted on this outcome, measures for speed and accuracy of reading were not included within the analytical scope of this study. In relation to the questions that were asked, these ranged from literal to inferential and gave a composite total. Scoring could have been disaggregated to provide specific information about the range of inferences that participants made compared to literal responses.

The absence of blinding within the design of the study is acknowledged. Arguably, the researcher could have influenced performance through prior knowledge of which participants were exposed to the Linguistically Complex Text. In part this was countered by the use of previously prepared scripts to ensure that spoken input and mediation was kept as uniform as possible across groups. A less positive possible outcome was that scripts may have led to less responsive adjustments to individual requirements for understanding information that might otherwise have occurred.

5.4.2 From participants to The Easy Read Project discussion

Specific extrinsic factors that were manipulated to address the challenges faced by people with IDs, i.e. the linguistic simplification of the texts, the nature of the mediation and the task itself could each have contributed to outcomes and merit further examination. These are addressed in Chapter 6 with reference to previous discussions threads from Studies A, B and C to provide a full analysis of findings in relation to the overall research question.

Chapter 6. The Easy Read Project discussion

The over-arching research question addressed by The Easy Read Project was: how effective is health-based ER literature in contributing to the construction of meaning for people with intellectual disabilities? Findings from studies A, B and C have been discussed in their corresponding chapters. These were appraised in Chapter 6 within the context of findings from Study D: The Easy Read Task. Strengths and weaknesses of the overall study were considered and finally, some indications were made about future directions for investigation.

Studies A, B and C considered factors associated with the extrinsic part of the process of constructing meaning from ER information. These investigated properties of ER material and the possible influences of presentational, linguistic and discourse features on understanding by people with IDs. Study D empirically examined the process whereby meaning was built through the reader's intrinsic skill set (reading, executive function, attention and background knowledge) supported by a further extrinsic factor: mediation. As Chinn (2016) demonstrated, ER material as an extrinsic factor within processes of health interaction has enjoyed more attention from publishers, producers and health professionals than the area of communication which relies on a wider range of influences, including intrinsic cognitive abilities and the kind of (extrinsic) mediating support provided. Findings from Study D showed that separating extrinsic and intrinsic factors is perhaps less useful than a consideration of how these factors interact to contribute to the construction of meaning.

Relevance Theory developed by Sperber and Wilson (1986) provides a flexible model of language and communication that incorporates both intrinsic and extrinsic factors and can be applied to explore the use of ER material with people with IDs (p. 74). A number of other models demonstrating the processes and outcomes of building meaningful interactions have emerged from the disciplines of cognitive science and psycholinguistics.

These have been discussed at various junctures in the current study. For example, cognitive and educational psychology has been responsible for theories that correspond to literacy processes (MacNamara and Magliano 2009) (see Introduction, p. 52 and Study D, p. 206). The consideration of literacy as a social practice (as outlined by Papen 2009, Introduction, p. 19), expanded the concept and included factors not necessarily identified as part of the phonological or semantic processes included in psycholinguistic models of literacy. These involved viewing literacy as socially constructed and shaped by different environments, habits and preferences of individuals. While this lent an extra dimension to the psycholinguistic model, a framework that provided better insight into the process of communication was required. The study of the pragmatics of language for the purposes of this discussion, widens the scope of meaning construction through incorporating a variety of intrinsic and extrinsic factors. Sperber and Wilson (1986) have put forward a model of communication that share some concepts with Papen (2009). Their (1986) treatise stems from a grounding in social sciences, cognitive psychology and linguistics. This served to clarify and contextualise central aspects from the findings in this study series and is extended in the following discussion.

6.1 Relevance Theory model of communication

Wilson and Sperber (2002) have proposed that assembling relevance from an interaction means that individuals use the cognitive resources at their disposal to make a series of decisions based on the existing evidence. Theoretically from their point of view, choice based on experience, preference and language capacity will naturally drive the reader's process for relevance. Using Relevance Theory (Sperber and Wilson 1986) imbues both producer and reader with choices in the construction of meaning that are not necessarily based on rational thought but on what could amount to a system of best estimates. ER material appears to be based, at best, on authors' perceptions of the readers' experiences, preferences and language capacity and is therefore founded on principles of subjective judgement. Admittedly, the use of coproduction may serve to counter this point, although any outcomes are dependent on the process of coproduction defined by

the interactions between facilitators and the user group. The element of choice and decision making that surrounds the production of ER material suggests that a shift in the power differential towards increased agency for people with IDs is necessary not only in the process but in the way people are represented in the final product. It also demonstrates that to make conscious decisions related to production and use requires a better evidence base for what works than exists to date.

As shown in Study D: The Easy Read Task, levels of ability in reading and their associated executive function, receptive vocabulary and reading comprehension all varied widely within the heterogeneous group of participants with IDs. Furthermore, findings revealed that different skill sets with varied capacities for reading and language amongst participants possibly affected the understanding of ER material. Construction of meaning at a deeper level was referred to within Relevance Theory (Wilson and Sperber, 2002) as meta-representational capacity, or the ability to represent lexical items (words) and make meaningful connections at a cognitive level over and above surface text level. For example, Wilson and Sperber (2002) proposed that developmentally, children learn to understand metaphor (often more easily visualised and concrete) long before they grasp the concept of irony (which is highly abstract).

They mapped meta-representational capacity onto three developmental levels: the beginner operates as a 'naïvely optimistic interpreter' and usually accepts their first interpretation of information as relevant. The 'cautious optimist' is able to process metaphoric language, but is still unable to successfully interpret untruths or ambiguities. The highest level is the 'sophisticated understander' who has a strong capacity to deal with ambiguities, deceptions and mismatches in construing relevance from the information provided (Wilson and Sperber 2002:42). The participant sample in Study D demonstrated a number of profiles that included 'naïvely optimistic' and 'cautiously optimistic' interpreters along with a few 'sophisticated understanders'. Individual capacity for language was established as critical to the successful construction of meaningful information for people with IDs. These developmental profiles described in Relevance

Theory (Sperber and Wilson 1986; Wilson and Sperber 2002) support the identification of different levels of information and communication processing identified through The Easy Read Project, specifically Study D: The Easy Read Task. Furthermore, they underpinned the idea that processing involves the interpretation of all the evidence available to a person at any given moment in time, including (but not specifically reliant on) the written or spoken word. Relevance Theory also incorporated a perspective on the interpretation of ambiguities that arise within the evidence available. As found in Study B and C, looking at linguistic features, ambiguity within the ER texts increased in tandem with a decrease in lexical diversity.

One example of such a linguistically acceptable ambiguity resulting from simplification in ER documents was the repeated use of the word 'people'. This could have meant the general public, or it could be referring only to people with IDs or to any other discrete sector of the population. Despite its broad meaning, it is unlikely to be identified as untrue. In Relevance Theory Wilson and Sperber (2002:25) described this use of ambiguous language as a flexible 'loosening' of meaning. It might be concluded that the drive for simplification has led to a 'loosening' of the meaning in ER material that leaves it open to multiple interpretations while at the same time maintaining linguistic acceptability and ticks the box as 'simplified'.

In conclusion, Relevance theory (Sperber and Wilson 1986) offers an established model of communication with enough flexibility for a closer examination of The Easy Read Project. It incorporates the processes of choice and decision-making in the construction of meaningful information that are not necessarily based on rational thought. Moreover, the model supports varying profiles of cognitive capacity as a critical influencing factor in the construction of relevance or meaning through spoken and written channels whereby the meaning constructed is ultimately something more than the sum of its parts. Ambiguities such as those found in ER material as a result of reduced lexical diversity and increased repetition, are therefore recognised within the model of Relevance Theory (Sperber and Wilson 1986) as generating loose and possibly less coherent meaning. Relevance Theory

upholds the idea that the issue of authorship and agency further contributes to the quality of constructed meaning where a tension exists between the author's experience and capacities and the perceived experiences and capacities of the target audience. Importantly for co-production, this implicates the process whereby ER material is co-constructed.

6.1.1 The cognitive environment

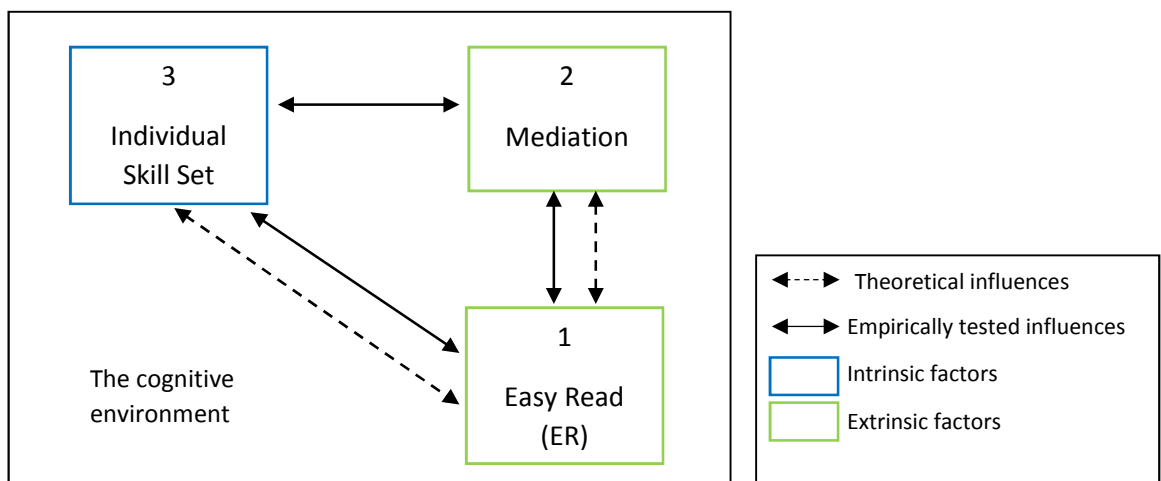
Human beings are programmed to make sense of the world around them. By gathering together pieces of information from cues in their immediate environment, and by mapping this on to personal knowledge and experience, they build relevant meaning for themselves. In adulthood, the schemas that people have created through experience and language are repeatedly drawn upon to make sense of information. For example, being invited to a birthday party will activate a schema that is about celebration, possibly cake, candles and presents. A conversation about this event will be reinforced by the underlying schema. For people with IDs, it might be challenging to create links from an ER document (as an extrinsic factor) to an experience for which no internal schema has been laid down.

Having established the principle of assembling relevance from both intrinsic and extrinsic factors, Wilson and Sperber (2002: 1) have argued that part of the process of pursuing relevance (or meaning) involves discerning what is more relevant out of the mass of detail available compared to other parts of the detail. Depending on how that detail is presented, positive cognitive effect could be easy or difficult to obtain from within a particular cognitive environment. For Wilson and Sperber (2002), the cognitive environment comprises all of the interpretable stimuli within an individual's physical, psychological or cognitive reach that together influence their understanding of a message. These have been referred to under the terms 'intrinsic and extrinsic factors' within the Easy Read Project. Elements that contribute to the cognitive environment can

combine to create a small or large positive cognitive effect. If only a small positive cognitive effect is generated, the information will be correspondingly low in relevance and less memorable.

The cognitive environment created in relation to the Easy Read Project studies is visualised in the schematic diagram below (Figure 6.1.1). It consists of intrinsic (blue bordered Box 3, Individual Skill Set) and extrinsic (green bordered Box 1 ER and Box 2 Mediation) factors. Two-way arrows represent the influences between factors within the cognitive environment. These demonstrate mutual influences between the ER material (Box 1) and Mediation (Box 2), and between the ER material (Box 1) and the Individual Skill Set (Box 3). Another solid arrow links Mediation (Box 2) with the Individual Skill Set (Box 3). Arrows with broken lines indicate where theoretical hypotheses were made about influences in contrast to solid lines which indicate the influences (or effects) that have been tested experimentally within these studies. A series of diagrams was used to build the following discussion. Each one demonstrates the central factors discussed within the corresponding section through the use of boxes outlined in green (extrinsic factors) and blue (intrinsic factors) and black two-way broken and solid arrows. Any factors (boxes) and influences (arrows) less prominently addressed in each section are displayed as shadows within the diagram.

Figure 6.1.1 Schematic diagram illustrating key components of the cognitive environment



As previously described (Introduction p. 57), Wilson and Sperber (2002) argued that achieving positive cognitive gain is directly linked to the cognitive effort involved in processing information. Using the skills and abilities available (represented in Figure 6.1.1 by the Individual Skill Set Box 3), a person makes sense of the direct and indirect information presented in spoken form (Mediation Box 2) or written form (ER Box 1) within the cognitive environment. Wilson and Sperber (2002) described how firstly all available input goes through a process of decoding. This is followed by networking that involves linking the information to background knowledge and experience. Possible hypotheses about the input are then constructed by the person, and processing stops as soon as he or she finds something that is acceptably relevant to them from the information provided. How far ER material positively influences this process is open to question.

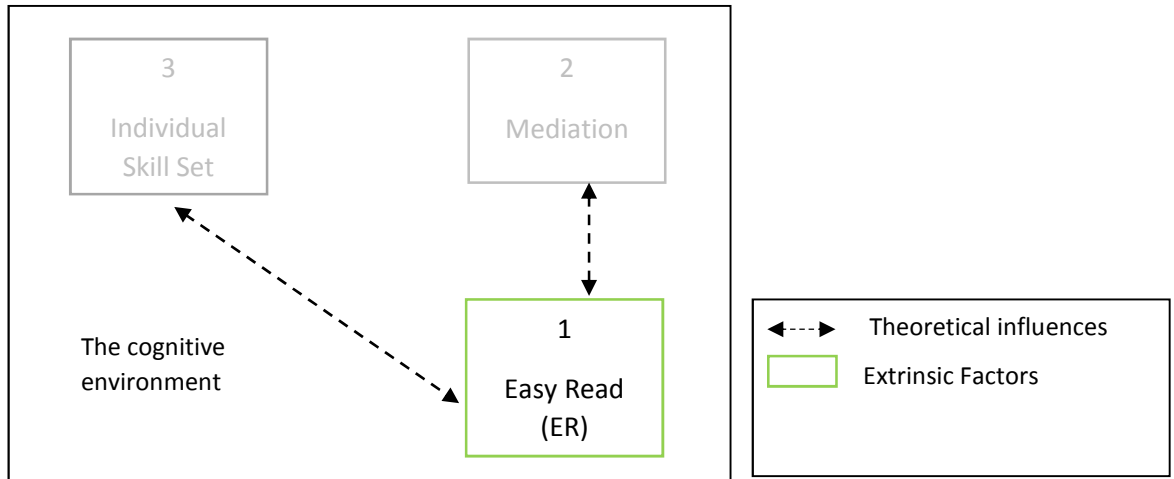
6.2 The Easy Read Task material

Ostensibly, in order to increase the potential of the target audience to understand information, DoH documents were adapted from N-ER into ER format (Figure 6.2.1. Box 1). As established through examination of some of the common ER guidelines in Study A (DoH, 2010; Inclusion Europe n.d.; MENCAP 2002), ER material purports to reduce cognitive processing by addressing extrinsic factors through adapting presentational features and simplifying language. The following section draws together findings from the first three studies in this series: Study A: The Survey, Study B: Linguistic Analysis and Study C: Discourse Features. Using Relevance Theory from Sperber and Wilson (1986), findings are considered with a view to their contribution to the construction of meaning at document level. Building on these, findings from Study D: The Easy Read Task, are also examined within the same framework.

ER (Box 1) in Figure 6.2.1 represents the DoH material investigated in Studies A, B and C. Broken arrows that link ER material (Box 1) with Mediation (Shadow Box 2) and the Individual Skill Set (Shadow Box 3) indicate that the influences discussed were

hypothetically and theoretically driven rather than empirically examined.

Figure 6.2.1 ER as a factor of influence within the cognitive environment



While the focus of Studies A, B and C was on the paper-based DoH documentation, results can be considered within the context of the cognitive environment. What characterised ER material in terms of its presentational features, production trends (Study A), commonly used linguistic features (Study B), and the nature of the language used in terms of patterns of power and discourse (Study C) is reviewed in terms of its possible influence on understanding. For Sperber and Wilson (1986), the more explicit the information, the lower the cognitive effort involved.

6.2.1 'Easy Read' information: explicit language

Clear differences were identified between ER and N-ER texts in Study A: The Survey. Features that typified ER material were shorter words and sentences, coloured images, larger font size and the increased amount of space used in layout. These presentational features demonstrated face validity in the ER version in terms of surface level differences, but they did not necessarily demonstrate explicit expression of meaning.

Very little empirical evidence existed to suggest what features, either singly or in combination could be associated with improved understanding of ER documents or the explicit expression of information. Indeed, evidence from 'safety and warning' research showed that the use of too many colours, pictures and words can cognitively over-burden the reader (Keyes 1993). This was consistent with research by Hurtado et al. (2014) and Williams and Hennig (2015) who showed that presenting information in typical ER format to people with IDs risked cognitive overload. In relevance theory (Sperber & Wilson 1986) the cognitive effort involved in making sense of such a document would quickly be judged to outweigh cognitive effect and the information would be deemed, in part, not relevant.

The wide variation in presentational features found in the ER DoH documents in Study A reflected the variety of advice given in published guidelines. Presentational variation could also have been a possible response to the diverse communication and interaction events that each document represented. Design variability in ER material in Study A was consistent with previous research into features (Oldrieve & Waight, 2015) and language (Bunning et al., 2010) on specifically adapted websites. Nevertheless, attempting to establish a universal model for information as suggested by an Accessible Information Standard (NHS England 2015) may compromise a more flexible approach that considers diversity of content and may ignore the complexity of an individually driven process for constructing meaning. Whether it is possible to employ explicit language in ER material so as to reduce cognitive effort, while also retaining flexibility in response to diverse need and maintaining informational content, has not been demonstrated.

According to Sperber and Wilson (1986), high levels of explicit language should positively influence the cognitive environment. Having identified language capacity in readers as key to the construction of meaning in Study D: The Easy Read Task, findings from the linguistic analysis of DoH documents in Study B takes on greater import. Significant differences between the ER and N-ER DoH material were evident at a linguistic level. As previously discussed, words and sentences were shorter and higher frequency, and a greater number of concrete words were found. Traditional readability measures were on

average much lower in the ER versions, reflecting the shorter word and sentence lengths. Collectively, this implied that the ER material contained a greater level of explicitly expressed information. However, the same patterns also led to a reduction in information content, increased ambiguity and a loss of lexical cohesion as revealed in Study B, the resolution of which would require relatively high levels of cognitive effort on the part of the reader. It could be argued that anyone functioning at the level of a 'naively optimistic interpreter' (Wilson and Sperber 2002: 42) would accept whatever superficial information was provided at this level and may stop processing language at the earliest interpretation of relevance without attempting to resolve the frequent ambiguities. Meaning processed at this surface level is unlikely to be well-retained (McNamara and Magliano, 2009). Moreover, if the resulting simplified text offered only superficial limited information, even a sophisticated reader with good language capacity may decide that the cognitive effort involved is not worth the effort of minimal informational gain.

6.2.2 'Easy Read' information: implicit language

Implicit messages require more inference on the part of the listener or reader than explicit language. The implicit information conveyed through ER texts (pictures, images and discourse) has not been well researched, although some studies have investigated aspects of understanding through picture interpretation. Often the use of images has had no effect on the comprehension of ER text as shown by Hurtado et al. (2014); Poncelas & Murphy (2006) and Williams and Hennig (2015). As previously explained, Grove (2014) (Introduction, p. 69) described how images that represented abstract concepts such as 'a meeting' were particularly open to interpretation and were easily misconstrued. If the reader did not have a cognitive environment (Figure 6.2.1) that was efficient and flexible enough to construct meaning from both implicit and explicit information, some of the message was lost. For people with IDs, this is a potential consequence when faced with ER material. Sperber & Wilson (1995:56) described implicit messages as 'vague' or 'non ostensive'. Arguably, making sense of non-ostensive, implicit language that has been created either through pictures or through the use of highly ambiguous, repetitive,

limited information (as described in findings from Study B) could make ER material difficult for both the reader and the mediator to understand.

Also largely overlooked in recent research is that implicit information is conveyed through documents at the level of linguistic discourse. How the ER texts functioned at this level compared to N-ER versions was addressed in Study C. Implicit information was charted through linguistic representations of people, actions, places and events. Findings also mapped evidence in the texts about the values, attitudes and aims of the authors in relation to the reader and the way that certain meanings were conveyed through the positioning of prominent topics as central or secondary within them. Much of this information was expressed at an implicit level where the reader might not consciously be aware of its influence. Nonetheless, representations of uneven power relationships, attitudes and emphases in the discourse of the language used were likely to be implicitly understood by both reader and mediator. The reduced agency of the reader was strongly represented within the ER DoH documents compared to the N-ER versions and could be an unintentional outcome of the simplification of language in ER material.

This could reflect a wider more invasive problem of power imbalance within interactions about health for people with IDs. Similar imbalances of power were found in studies of communicative health literacy in Chinn's (2016) work. She recognised inherent power differentials evident in interactions between professionals and people with IDs in several studies investigating communicative health literacy. Relevance theory (Sperber and Wilson 1986) argued that much of the search for relevance occurred at a subconscious level. For example, 'please bring me the blue cup on the table' is ostensive and explicit. However, 'only I can drink out of the blue cup' and reaching out a hand towards it, is non-ostensive and implicit and carries evidence and expectation of deference in the listener. Here the influences of mediator and interaction with the reader are realised in relation to the ER material.

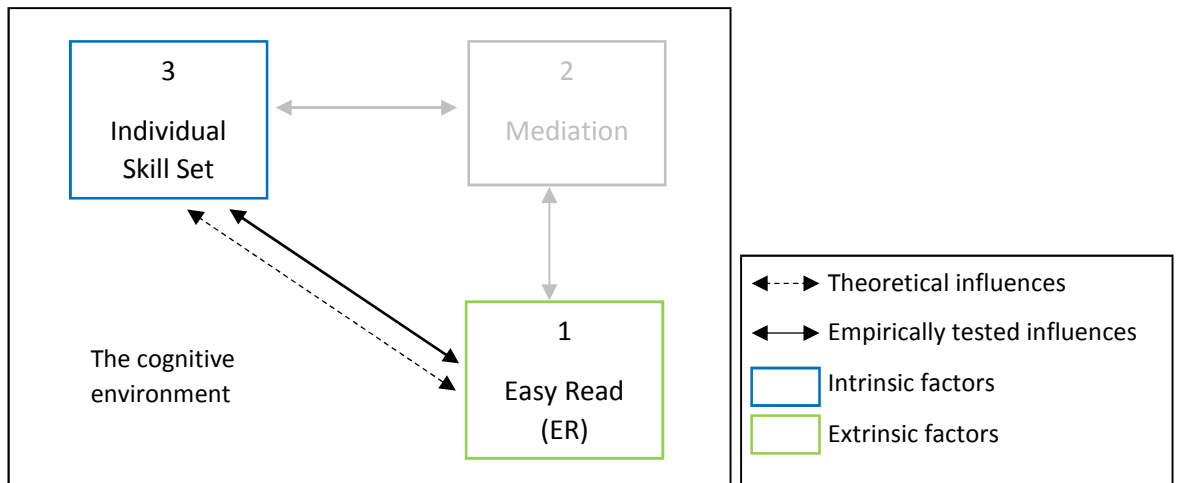
Despite the clear power differentials identified, evidence has also shown that ER documents matched up to reported audience preference, particularly in terms of layout and presentational features as expressed in Owen (2006), Tarleton (2005) and Williams and Hennig (2015). Encouragingly, within Relevance Theory (Sperber and Wilson 1986), preference contributes to positive cognitive effect for some communicators. For others who reported they found the format 'childish' (Buell 2015, Oldrieve and Waight 2016) ER did not fulfil a preference and may not have had a positive cognitive effect. The information would therefore not be considered relevant. The evidence reviewed from Studies A, B and C could only theoretically hypothesise about how well the DoH documents were matched to the cognitive abilities of the readers. It might be concluded that the ER material studied was different to its N-ER comparators but research evidence does not suggest that the changes made will necessarily help people with IDs to understand the information in them and at times it might even hinder the process. Empirical investigation was required to better ascertain whether ER material balanced cognitive effort with cognitive gain and made an impact on the construction of meaningful information.

6.3 The Easy Read Task

6.3.1 Influence of the individual skill set on the comprehension of ER material

Figure 6.3.1 below represents the influences between the Individual Skill Set (Box 3), the ER material (Box 1) and Mediation (Box 2) within the overall cognitive environment. Influencing links are demonstrated by solid arrows indicating that they were empirically investigated and these are discussed in the following section. Mediation (Box 2) and corresponding arrows are in shadow indicating that they will not be directly addressed in this part of the discussion.

Figure 6.3.1 ER and the individual skill set as influencing factors within the cognitive environment



Based on the findings from Studies A, B and C, it was hypothesised that linguistic simplification of text was unlikely to make a difference to understanding, but that mediation would increase reading comprehension of the ER material used in The Easy Read Task (Study D). Indeed, findings revealed no significant differences between the four conditions suggesting that neither simplifying the text alone, *nor* providing mediation made any difference to how easy it was for participants to construct meaning from the material. Although this finding was expected, it also raises several questions about the participant sample, the levels of complexity between the two ER documents used in the task and the material in relation to the skillsets of participants.

In terms of the participant sample, this was carefully stratified and participants were allocated to conditions on the basis of reading ability. All four groups were equally constituted for reading comprehension and this correlated with vocabulary measures so skill set within the sample should not factor in the results. It could be argued however, that the two texts were not different enough to demonstrate a difference in performance. Alternatively, it was possible that neither the Linguistically Simple nor Complex ER text (Box 1) was sufficiently well matched to the variable language and reading levels (Individual Skill Set Box 3) of the participants such that it made a significant difference to comprehension.

6.3.2 Linguistic influence on the comprehension of ER material

Whether the two texts were linguistically different enough to measure a difference in participant comprehension was considered as a possible explanation for the lack of significant differences between the four groups. The following two sections (Linguistic influence on comprehension and Picture influence on comprehension), address the relationship between Box 1 (ER) and Box 3 (Individual Skill Set) in Figure 6.3.1 delineated by a solid black line.

Simple and Complex Texts were prepared to emulate authentic ER material published by the DoH to ensure face validity. Presentational and layout features were used that were also as close as possible to the trends found in the DoH documents reviewed in Study A: The Survey. They were devised to match linguistic features and levels taken from the most linguistically complex and simple texts in the DoH sample.

Traditional readability measures were taken and Coh-Metrix TERA profiles were generated for each text (as described in Study D). The Easy Read Task texts were manipulated to achieve Flesch Kincaid scores of Grade 4 and Grade 14. Even the lower measure (Grade 4) was equivalent to the reading and understanding ability of an eight year old child without IDs. Given that the mean estimated reading age of adults with IDs (who self-identified as readers) was around the equivalent of age six (Jones 2006; Moni and Jobling 2001), it would seem that, based on this measure, neither the Simple nor the Complex ER text in Study D was matched to the cognitive abilities of the target audience. However, although Flesch Kincaid measures demonstrated that the Linguistically Simple Text used shorter words and sentences than the Linguistically Complex Text, findings from Study B: Linguistic Analysis and Study C: Discourse Features suggested that the *type* of shorter words and sentences chosen, and *how* they are used could also impact on understanding. The idea that meaning can be conveyed through other cohesive structures was supported by the TERA profiles of both Simple and Complex Texts.

Counter to what might be assumed by the readability measures, the DoH simple and complex templates did not differ widely on all of the TERA measures (p. 183). The Simple Text demonstrated much higher narrativity and increased syntactic simplicity in contrast to the Complex Text. The texts did not differ on word concreteness nor did they differ substantially on referential or deep cohesion. The main differences therefore, were surface level modifications related to syntactic simplicity in keeping with the original DoH model texts. It might be argued therefore, that The Easy Read Task was only able to account for the effect of surface level changes through simplified syntax, and to a lesser extent, increased narrativity. Clearly, as expected, neither of these modifications made any significant difference to the participants' understanding of the information presented. The Easy Read Task was not successfully able to measure how differences in word concreteness, referential or deep cohesion influenced understanding due to the restrictions presented by recreating a low cohesion text with highly concrete vocabulary. Adapting the way referential and deep cohesion are constructed and the influence of these on understanding of ER material are yet to be discovered.

In Relevance Theory (Sperber and Wilson 1986) terms, the two texts showed little difference in how they helped to decrease cognitive effort, or to increase cognitive gain. Nevertheless, shortening sentences and words which leads to syntactic simplicity were included in the modifications frequently advised in published guidelines for producing ER material (DoH, 2010; Inclusion Europe, n.d.; MENCAP, 2002). Syntactic simplicity and shorter words and sentences were also among the most common features identified in Study B which analysed linguistic features. Evidence demonstrated that little attention has been given to the effects that simplification of syntax can have on referential and deep cohesion and coherence or how these might impact understanding.

The process of simplifying documents for the purpose of this experiment also raised the question of restrictions imposed by the choice of subject matter. The same subject matter (healthy eating) was used in both Simple and Complex Texts in Study D and was chosen to provide maximum possible familiarity. The increased cognitive effort involved in

processing more complex referential information in a text with complex abstract information may be balanced if the topic is very familiar. This would increase the possibility of perceived cognitive gain. Familiarity with the topic and previous personal experience could, according to Sperber and Wilson (1986), contribute favourably to the cognitive environment and to the process of finding relevance and achieving meaningful understanding. There is an implication that the presentation of novel content might not provide the same favourable influence on understanding. This further supports the argument that creating ER material that is responsively adjusted for purposes of comprehension does not rely merely on surface level simplification of language. It is possible that the topic chosen for The Easy Read Task was overly familiar to participants. High levels of background knowledge might have ruled out any effects from simplified text. The influence of complexity and familiarity of subject matter on comprehension warrants further attention.

6.3.3 Influence of pictures on the comprehension of ER material

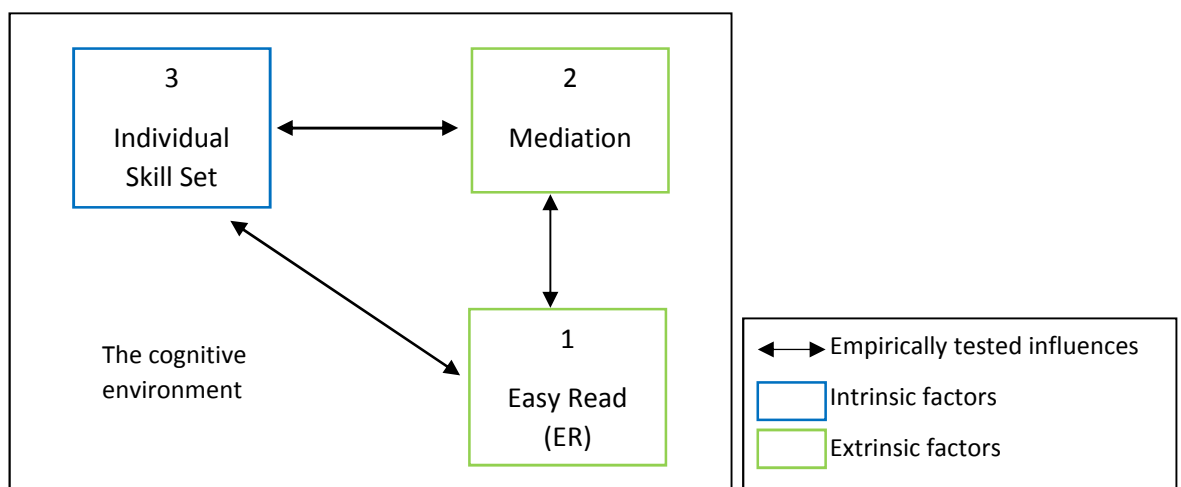
While the influence of pictures and images on comprehension was outside the scope of The Easy Read Task, they typify ER material and were therefore included in both the Simple and Complex Texts. Their presence might also explain the similar outcomes across participant groups but not necessarily because they served to make meaning explicit from the text. Pictures might have cognitively overloaded the good readers due to the demand for splitting attention between text and images. The poorer readers might have simply ignored the text (seeking for cognitive effect over cognitive effort) and focused on the pictures thereby achieving a higher score (consistent with Hurtado et al.'s (2014) research). Using pictures presented an opportunity for implicit and explicit influence on the understanding of information within the participants' cognitive environment depending on how easily the pictures related to the words used. For example, 'carrot' was easily represented in both Simple and Complex Texts due to being concrete and imageable, compared to 'the government' in the Complex Text which was comparatively abstract.

As far as possible, the same pictures were used in both the Linguistically Simple and the Linguistically Complex Texts so as to reduce confounding. However, more work is needed to address the level of implicit and explicit information conveyed through the use of pictures in constructing meaning, as well as the way in which people with IDs visually and cognitively process the various competing stimuli on the page. As expected, there was no clear evidence from The Easy Read Study to demonstrate that the pictures encouraged positive cognitive effect, nor that they decreased cognitive effort. Human solutions in the form of mediation however, have been identified as both critical and effective in the construction of meaning (Chinn 2016).

6.3.4 The influence of decoding support and mediation on the skill set in the comprehension of ER material

Figure 10 below demonstrates the influences (1 - 3) between the Individual Skill Set (Box 3) in relation to the ER material (Box 1) and influences between Mediation (Box 2) and both the Individual Skill Set (Box 3) and the ER material (Box 1) (2 – 3 – 1) All of the arrows in this diagram are solid, representing influences that were empirically investigated.

Figure 6.3.2 ER, mediation and skillset as influencing factors within the cognitive environment



Consistent with The Simple View of Reading described by Turnner & Gough (1986), processes for understanding text depend on an efficient phonological decoding/ word recognition route and an efficient lexical /semantic route. All participants in Study D received unlimited support to orthographically decode the words on the page. This was referred to as decoding support and related to the process whereby a reader recognises letters and can put them together to form a word. Within this model, decoding of letters into words is separate from the activation of memory and lexical information that allows meaning to be attached to the words (See p. 54). Input to all participants at this level aimed to reduce the effect of participant decoding skill on comprehension by verbally providing any words for the readers that they were unable to read aloud. Sixteen participants out of sixty chose to read silently and they could have been disadvantaged by indicating less consistently when they could not read words.

Decoding support

It is possible that participants who found it difficult to decode the words orthographically as described above, because of weaker reading skills requested more decoding help when faced with both the Simple and Complex Texts than those who had better reading skills. The presence of more difficult words in the Linguistically Complex Text could also have led to higher requests for decoding support by participants in those groups. This meant that relative to the Linguistically Simple Text, positive cognitive effect could have been increased through more phonological support given with the more Complex Text. Thus the Linguistically Complex Text was made less effortful for weaker readers in comparison to the Simple Text where participants might have relied more on their own decoding skills. Beck (1984) showed that when faced with the dual task of decoding and understanding text, participants focussed on decoding to the detriment of their understanding of the texts. For the readers of the ER material who found the decoding stage challenging, the reading process may have become weighted towards phonological decoding at the expense of meaning construction and comprehension was thereby compromised.

Reciprocal Reading as a mediation model

In contrast to the decoding support which was given to all participants, literacy mediation was controlled across groups in Study D to ascertain its effect on comprehension. It was therefore given to only half of the participants (in Conditions 1 and 2) and involved implementing the modelling section of a reciprocal reading method. Reciprocal reading, devised by Palinscar and Brown (1984) comprised four main strategies: summary, clarification, generating questions and prediction. This method was successfully shown to increase reading comprehension (Alfassi et al., 2009; van den Bos et al., 2007) and reading motivation (Reichenburg 2012) in adults with IDs through dialogue and interaction. In spite of implementing a systematic form of reciprocal reading in Study D, no significant difference was found in performance on comprehension questions between the four conditions. Mediation in this case had no effect on the participants' ability to understand either Simple or Complex ER information. Why this should be the case warrants examination. The nature and quality of the mediation, how it corresponded with the participant individual skillset, and the relative contribution to the overall process of reading comprehension are discussed in the following sections.

Participants were informally observed to be mainly passive during mediation as evidenced by the number of mediation requests initiated. Although this has been identified as a pattern in the reading behaviour of people with IDs (Chinn, 2016; Gersten et al., 2001; Reichenburg, 2012), the extent of the passive response to mediation in this experiment was unexpected. The number of communication initiations, queries or requests for clarification made by participants related to the text during mediation was noted. Only two participants asked for clarification. No other initiations, queries or requests were made. This, combined with requirements to control and standardise the mediation to maintain a robust methodology meant that in practice, there was little dialogue or interaction with which to gauge understanding of the mediated information.

It is also worth noting that despite being reading to learn rather than learning to read (Alfassi et al., 2009; van den Bos 2007), reciprocal reading is a structured interactive

method of literacy instruction for improving reading skills as distinct from a simple explanation of the topic. Co-construction of meaning, as defined by Grove (2014), requires the active participation on the part of both or all of those involved in the construction process. Wilson and Sperber (2002) have maintained that each interaction despite being replicated at different times will generate the construction of a distinct set of relevancies. Seeing the same ER leaflet twice could therefore be expected to have different effects each time. Furthermore, the range of implicit messages conveyed through the subtleties inherent in any new interaction between different people will also vary on each occasion. Not only were participants given the ER documents for reading only once, but the 'reciprocal' part of the mediation present in this experiment was limited. The acts of summarising and explaining were maintained in the domain of the researcher. In this sense, very little agency was attributed to the participant and attention was not drawn to the possible interactivity of the task for participants.

The level of mediation delivered in this case could be judged to have fallen short of tapping into the deeper level processing necessary to activate links for a more successful construction of meaning. There was little scope for developing mediation to help participants to create their own situation models for understanding. McNamara and Maglioni (2009) used the CI model of reading to demonstrate the importance of this. Making links and inferences through reference to personal experience or examples is also outlined by Wilson and Sperber (2002) as a crucial factor in reducing cognitive effort and increasing cognitive effect. As such, it seems that creating schemas from life experience and language, or situation models from text is an important area for future research and development. The incorporation of more dialogue that was specifically tailored to the language capacity and experience of the participants might have allowed for a deeper construction of meaning and better comprehension. Failure to tap into deeper understanding could explain why no difference was shown between the groups that received mediation and those that did not. Reports of success in the use of mediation to improve comprehension of information with people with IDs (Alfassi et al., 2009; Chinn 2016) and the lack of difference it made to participants in The Easy Read Task also

suggested that the quality of the mediation offered was critical to how information might ultimately be understood.

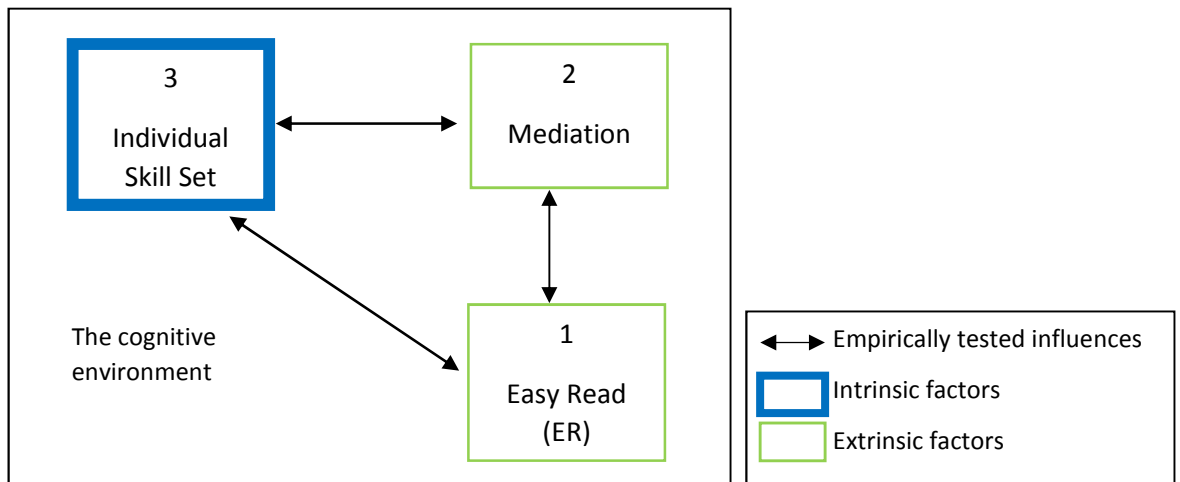
There is also a possibility that mediation *did* have a positive cognitive effect on poorer readers, thus raising their comprehension scores in line with the good readers for whom mediation could have had a negligible influence. Unfortunately the measures in this study were not sensitive enough to provide demonstrable evidence of what elements (if any) of the support and mediation processes specifically enacted on the individual skillset to contribute to similar comprehension scores across all conditions.

According to Relevance Theory (Sperber and Wilson 1986), personal interaction brings a number of additional and variable stimuli into the cognitive environment, many of which can be construed as implicit and these will require interpretation and inference. In line with this model of communication, mediation could have the effect of either *reducing* or *increasing* cognitive effort.

6.3.5 Linguistic and mediation influence on the comprehension of ER material

Despite the fact that no differences emerged between the four conditions in Study D, a significant interaction was revealed when Mediation and Linguistically Simple Text were present and when data were controlled for the effect of vocabulary. Figure 11 represents the same influences and links as shown in Figure 10. However, the Individual Skill Set in Figure 11 (Box 3) has a prominent blue border to show that language capacity, within the Individual Skill Set had the most significant influence on the construction of understanding of information presented in the Linguistically Simple ER format (Box 1) with Mediation (Box 2).

Figure 6.3.3 Individual skill set as the critical factor in in the cognitive environment for constructing understanding



There was no significant interaction when the data were controlled for reading ability. This suggested that language ability (identified by vocabulary measures in this study (BPVS)) underpinned comprehension of the ER information in this Task more strongly than reading comprehension ability (YARC). Despite the fact that reading comprehension ability and vocabulary were correlated strongly in Study D, vocabulary knowledge was still shown to have a stronger positive effect on The Easy Read Task scores than reading comprehension ability when the text was Linguistically Simple. The interaction was also not evident in the condition Linguistically *Complex* Text With Mediation. It is unclear why mediation did not have a similar effect on improving participant understanding when they were faced with the text that was Linguistically Complex. One explanation could be that readers looking at the complex material had to devote more of their attentional resources to reading compared to those who had the Simple Text. The participants with the Complex Text therefore had fewer attentional or cognitive resources left to benefit from the mediation that was offered.

To summarise, increased comprehension resulted when extrinsic influences in the form of Linguistically Simple ER text and Mediation were present. However, there was a sizeable caveat in that vocabulary knowledge underpinned this interaction. Naess et al. (2012)

reported that vocabulary knowledge in children with IDs predicted reading ability more strongly than phonological awareness. Both Naess et al (2012) and van Tilborg et al. (2014) identified vocabulary knowledge as a compensatory factor for children with IDs in trying to make sense of written information (p. 59). It might be suggested that better vocabulary knowledge increased the ability of participants in the ER study to relate the meaning of words to real world experiences and to build a situation model (McNamara and Maglioni 2009) from the text. Linking meanings from different words and phrases activates related concepts and ideas. The subsequent mapping of these onto prior knowledge and experience leads to a fuller construction of meaning from what is read. It can be concluded that although Mediation and Linguistically Simple Text supported the understanding of the Easy Read Task, the most important aspect that contributed to the construction of meaning was the intrinsic level of vocabulary knowledge in the skill set of each participant. With respect to Sperber and Wilson's (1986) theory of relevance, the most influential factor for achieving high cognitive effect from ER material in The Easy Read Task was the ability of participants to apply cognitive effort. Within the cognitive environment, findings from Study D demonstrated that language capacity was likely critical in reducing cognitive effort and increasing cognitive gain. How effectively linguistic concepts have been laid down with meaning in the lexicon and attached to the letter strings and corresponding sounds used in reading define how efficiently a reader can make sense of text. This is further strengthened by cognitive schemas developed from real world experience and knowledge that serve as a resource for constructing meaning and relevance from print.

The process of bringing information to people with IDs is therefore suggested to be multi-dimensional and extends further than the printed word, regardless of how 'simplified' it may be or whether it comes with the addition of supporting graphics. Findings have implications for the development of ER material and point to the need for specific changes in emphasis from design to a focus on how well people can understand language or be supported to understand it.

6.4 Critique of The Easy Read Project

Specific limitations relevant to each study have been outlined after the concluding sections in their corresponding chapters. Overall strengths and weakness of the four studies are considered below.

The Easy Read Project has contributed to our understanding of ER material published for people with IDs in the UK. It examined a full set of ER health-related literature underwritten by a government department and available in the public domain. By analysing the presentational, language and discourse features of this material, a solid evidence base for what typifies ER material has emerged with trends and patterns recognisable throughout. Building each study out of the previous one strengthened the overall results of The Easy Read Project and developed a replicable system for analysis at multiple levels, from linguistic and discourse features in ER material (Study B and C) to a randomised experiment in Study D. Collectively, the four studies addressed a wide range of issues from the level of paper to the level of participant understanding.

A consultancy group was created to advise on the material used for Study D: The Easy Read Task. Arguably, more involvement by people with IDs in the preparation stages of The Easy Read Task through the use of co-production processes used by a major producer of ER material (e.g. Change) would have served to mimic actual development processes in use and would have lent more authenticity to the materials. Furthermore, collaborative decisions about what presentational aspects to include in Study A: The Survey, could have provided a more reliable evaluation of features perceived by the target audience as important for inclusion. The number of variables surveyed was limited to contain the study within manageable parameters. Other features mentioned in published guidelines (DoH, 2010; Inclusion Europe, n.d.; MENCAP 2002) that were not included in the survey, but that might affect understanding were the use of bullet points and the avoidance of questions and negative constructions.

Recruitment of sixty participants to the empirical study (Study D: The Easy Read Task) was not without difficulties and although a larger sample could have generated stronger findings, the time constraints imposed on the study did not allow for further recruitment. Attention to robust and reliable procedures in Study D possibly narrowed the sensitivity and flexibility required for successful mediation, but did provide a replicable model of mediation support and protocol which might be adapted for further use. Future research might consider other models of mediation and is expanded on below in Section 6.6.

Finally, research based on theoretical models of literacy, reading, language and communication with participants with and without IDs have demonstrated the complexity of the subject area. There are inherent difficulties in attempting to isolate different processes from within aspects of cognitive function and language processing for research. Indeed, Protopapas (2013: 197) has called attempts to do so a 'futile' endeavour. The combination of reading, interaction and responding to questions in The Easy Read Task added further complexities to the investigation of reading comprehension in Study D that brought with them more influencing extrinsic factors that were not controlled. These included memory skills, auditory processing abilities, as well as confidence under test situations and motivation. On balance, given the variation found in paper ER documents (Study A: The Survey) and the complexities of addressing cognitive processes in reading and language function, The Easy Read Project achieved modest outcomes based on aims and methods that were designed to be as robust as possible.

6.5 Conclusions and implications

It appears that the authors of ER health-related literature have achieved documentation that is distinctive from its N-ER counterparts. Through the use of a particular presentational format investigated in Study A: The Survey, ER material represented a document that was clearly different from its N-ER comparator. It displayed lower density text, larger font size, more white space and coloured pictures and images. In terms of face validity it characterised a document that might be perceived as requiring less cognitive

effort to understand in comparison to the N-ER version. The ER material included in Study A varied widely in style and presentation but it resembled the type of ER material that was reported to fulfil the preferences for information production and presentation expressed by many who used it. As demonstrated by the range of production companies involved in creating ER material, there is both the will and desire for a continued market. However, there is no evidence to demonstrate what combination of surface level changes rendered through the manipulation of presentational features makes a difference to the construction of meaningful information for people with IDs.

Through the analysis of linguistic features in Study B, findings demonstrated that producers of ER material have succeeded in creating a text that differs significantly from its N-ER comparator on surface level linguistic features (short words and sentences, low word variation, repetition of vocabulary and grammatical structures). Notwithstanding, a closer analysis revealed that these features led to a reduction in information, increased ambiguity and a loss of cohesion. Together, these were considered likely to complicate rather than promote the process of meaning construction for readers with IDs. Again, ER material in its current linguistic form was demonstrated to fall short of achieving a version that reliably represented the information in its N-ER comparator.

Study C then looked more specifically at how changes identified in Study B such as reduced information, ambiguity and assembly of cohesive devices affected the nature of the ER and N-ER text discourses. Again several key differences were identified. Detail was compromised and cohesion was also negatively affected due to the reduction of sentences and repetition of terms. The representations of people and events revealed clear power differentials between author and reader in the ER versions. Thus ER materials appear to have compromised the agency of the target audience, which may be an artefact of the surface-level simplification process mentioned, e.g. the repetition of referents and the use of concrete terms. There is a need for increased awareness surrounding the consequences of linguistic simplification when decision-making about the

relevance of information in ER material demonstrates both reduced cohesion and an imbalance in author - reader power.

Findings from The Easy Read Project have revealed that getting ER material right in terms of presentational, linguistic and discourse features is important. In its current form, ER DoH material ticks several policy boxes and serves a social purpose, all of which has been acknowledged. Unfortunately, there is little evidence that manipulation of surface level features achieves understanding of ER information. Attention to the construction of language and the nature of the linguistic choices made in ER, revealed a document type with little consideration to the cohesive mechanisms that relate to deeper understanding, or to the unequal power differentials perpetuated. It can be concluded that whether ER material was assessed to be simple or complex on the basis of surface level linguistic features, there was no difference in the readers' responses. This means that the variation seen in ER materials probably does not make a difference to the readers' understanding. Surface level presentational and linguistic features are not the critical factor. However, empirical findings from the experimental study (Study D) showed the importance of individual language capacity in the construction of meaningful information. Linguistically simple ER material and mediation were demonstrated to contribute to a complex process where real understanding was shown to depend on the language ability of the reader and the skill of the mediator in adapting and responding to the individual's level of language. Until both ER material and mediation processes are adjusted to account for the level of individual language capacity that people with IDs bring to the task, they cannot be judged as adequately fit for the purpose of constructing meaning from health related information.

6.6 Future research

Based on these findings, increasing the research evidence for what makes ER material useful and functional in the process of constructing meaning requires a shift in emphasis

from design alone, to how design contributes to the construction of information by people with IDs alone or through mediators.

Presentational and linguistic features such as those identified in Study A: The Survey, Study B: Linguistic Analysis and Study C: Discourse Features warrant further empirical investigation. How different combinations of features contribute to understanding could vitally influence production trends and furthermore could confirm their continued use or provide better alternatives. The current empirical study has provided vital baseline data on which to build further research. It points to a need for investigating what combination of elements within the cognitive environment may have the most positive impact on the understanding of ER information. The two main areas indicated are 1. an exploration of the influence of different cohesive devices in ER text on the construction of meaning, and 2. an investigation into what comprises successful mediation.

Primarily, in terms of language, the effect of adapting text cohesion requires further testing. This could be achieved through recreating similar experiments to The Easy Read Task, but where cohesive devices in one set of ER documents are systematically manipulated to avoid repetition and reduction, to increase narrative structure and to elaborate and explain terms where this would linguistically add to meaning rather than remove it. Although pictures and images were identified as one of the regular features of ER material, they were not directly included within the scope of the current project. The role they play in meaning construction, particularly how they support text cohesion or otherwise, warrants further deliberate investigation. Additionally, the unequal power differentials recognised through linguistic representations in ER material as an unintended consequence of simplification might be analysed through further empirical study and could be directly suited to participatory investigation with co-production teams.

Secondly, mediation models for facilitating the understanding of ER information demand deliberate and in depth attention. Relevance Theory (Wilson and Sperber 2002) has provided a flexible model of cognition and communication for continuing to explore the processes of mediation. If all available evidence in an interaction is processed by an individual who brings their own capacity (skill set, experience, knowledge and cognition) in pursuit of personal relevance, this points to the need for a new, more dynamic and creative model of mediation. The focus of such a study needs to be on how language (spoken and written) and cognitive skills (of both participant and mediator) work together to reduce cognitive effort and increase cognitive gain whereby a point of best relevant understanding is reached by the participant. Design might take the form of running empirical workshops on certain topics that use the concepts of Relevance Theory to construct understanding alongside control group workshops that are presented with less responsive information.

Those acting in supportive roles need access to practical and useful information about: the receptive and expressive language skills of the individual (e.g. lexicon, morphosyntax, pragmatics), their reading abilities, and the likely schema laid down related to experiences that share some commonality with the topic. These would form the base level from which support could operate in the Relevance Theory groups. An examination would be warranted of the mediation processes, their impact and their relationship to base level information.

Co-production actively involves the user group whilst supporting the concept of engaged development. Since the initiation of ER material, consensus development at this level has given the mark of authentic approval to ER documents. The Accessible Information Standard (NHS England 2016) has stipulated that all ER material developed for use by people with IDs must now be co-produced. To date there is little research into the processes that different co-production groups rely on in their development of materials. They would bear further investigation with particular attention to how much focus there is on the effects of textual coherence and the influence of mediation.

There is a need for robust research to run alongside the continued production and co-production of ER material. At present, designers and producers lead the market in ER production. A better counterbalance is required to create a more evidence-driven market.

6.7 Realising the value of ‘Easy Read’?

People with IDs who experience difficulties with language and literacy are vulnerable to missing or misunderstanding crucial information about health when it is given to them in written form. ER material has emerged as one response to address this issue. Little previous research evidence was found to demonstrate how far ER material in the UK contributed to the process of constructing understanding. The Easy Read Project therefore embarked on three paper based studies specifically investigating DoH ER material and examined presentational, linguistic and discourse features found in ER documents and their N-ER paired versions. The final experimental study investigated the effects of simplified language and mediation on the construction of meaning by participants with IDs. A number of other intrinsic factors and possible extrinsic factors were identified as influential in contributing to the construction of understanding. The critical and pivotal factor was found to be participants’ capacity for receptive language.

The continuing development of ER production, the positive response of user groups towards it and the recent drive from legal, policy and service organisations (NHS England 2016) for its enduring use suggest that ER material is here to stay. It behoves all of those involved in its production and dissemination to make a closer examination of the language capacities and processes involved in understanding information presented in ER format. Without a better appreciation of the complex interactions between extrinsic and intrinsic factors in the construction of meaning from information, ER documents will continue to function superficially as no more than a sticking plaster (Rowland and Schwiebert 1990) or ‘cosmetic device’ (Walmsley 2013:17) over a difficulty that requires more serious attention. Greater input is required from the disciplines of linguistics and psycholinguistics to develop ER material that is fit for purpose in terms of how language is

constructed. Furthermore, research that begins by defining the strengths and weaknesses of language capacity and communication profiles of ER users may more effectively get to the root of how meaning is constructed with and without mediation in healthcare.

There are human and financial resource and cost implications to the on-going production of ER material. People with IDs, their family members, carers, and health professionals ultimately bear the burden of these expenses. This calls for more critical reflection on how ER resources work to help or hinder the everyday construction of meaningful understanding. The simplification of ER information has been shown to be rather more complex than many designers, producers and publishers realise. It requires a closer understanding of how language creates meaning and what happens to meaning when simplification rather than understanding becomes the goal. A quote by Shakespeare (1996: 118) attributed to Einstein, 'Make it as simple as possible but not simpler' communicates one of the central messages that has emerged from The Easy Read Project.

Abbreviations

AAC	Alternative and augmentative communication
BPVS	British Picture Vocabulary Scales
CA	Conversation analysis
CELEX	Centre for Lexical Information
CI	Construction-integration
DoH	Department of Health
DS	Down Syndrome
ER/ N-ER	Easy Read / Non-Easy Read
IASSIDD	International Association of Scientific Studies in Intellectual and Developmental Disabilities
G/N	Given/ New
ICD-10	International Classification of Disorders -10
ICT	Information and communication technologies
IDs	Intellectual disabilities
IFLA	International Federation of Library Associations and Institutions
IRAS	Integrated research application system (NHS)
L.(+number)	Line reference to text
LDRI	Learning Disability Research Initiative
LSA	Latent semantic analysis
MENCAP	National leading UK charity for people with IDs
MLTD	Measure of lexical textual diversity
MRC	Medical Research Council
PMID	People with multiple and intellectual disabilities
SFL	Systemic functional linguistics
SRV	Social role valorisation
TERA	Text Ease and Readability Assessor
TTR	Type token ration
UNESCO	United Nations Education
UPIAS	Union of Physically Impaired Against Segregation
W3C	World Wide Web Consortium
WCAG	Web Content Accessibility Guidelines
WM	Working memory
YARC	York Assessment of Reading Comprehension

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Appendices

Appendix Chapter 2. i The Survey DoH documents

CODE	DOCUMENT NAME	YEAR	Excluded Stage 1 Survey	Excluded Stage 1 Title matching	Excluded Stage1 Text Sampling
1E	Better services for people with an autistic spectrum disorder ER	?			
1N	Better services for people with an autistic spectrum disorder N-ER	2006			
2E	The Bournemouth safeguards ER	2006			
2N	The Bournemouth Safeguards N-ER	2006			
3E	Caring for our future ER	2012		One is pre consultation paper, the other is post . No match	
3N	Caring for our future N-ER	2011			
4E	Choosing Health ER	2004			
4N	Choosing Health N-ER Exec Summary	2004			
5E	Cold Weather Plan for England ER	2012			
5N	Cold Weather Plan for England N-ER	2011			
6E	Deprivation of Liberty Safeguards and you ER	2009			
6N	Deprivation of Liberty Safeguards N-ER	2008			
7E	A guide to getting direct payments from your council ER	2009			
7N	A guide to receiving direct payments from your local council	2009			
8E	Direct payments uptake project ER	2006			No section of min 100 words

8N	Increasing the uptake of direct payments N-ER	2006		in ER version
9E	Seasonal flu ER	2011		
9N	Seasonal flu N-ER	2009		
10E	Questions to ask when you go to the doctor or hospital ER	2007		
10N	Questions to ask N-ER	?		
11E	Health Action Planning ER	2009		Not enough close matching titles (3)
11N	Health Action Planning N-ER	2009		
12E	Healthcare for all ER	?		No matching titles
12N	Healthcare for all N-ER	2008		
13E	Healthy Lives, healthy people ER	2011		
13N	Healthy Lives, healthy people N-ER	2011		
14E	Human Rights ER	2009		No matching titles
14N	Human Rights N-ER	2009		
15E	Independence, wellbeing and choice ER	2005		
15N	Independence, wellbeing and choice N-ER	2005		
16E	Joint Investment Plans ER	2001		
16N	Joint Investment Plans N-ER	2001		
17E	Making Lives better ER	2004		Available Non-ER document does not correspond to ER document
17N	Making Lives better N-ER	2004		
18E	The Mental Capacity Act ER	?		
18N	Mental Capacity Act N-ER Executive Summary	2005		
19E	Mental Health bill ER	2006		
19N	Mental Health bill N-ER Executive Summary	2006		
20E	Mental health in the future ER	2009		

20N	Towards a shared vision for mental health N-ER	2009	
21E	About MRSA screening ER	2009	
21N	MRSA Screening N-ER	2009	
22E	About MRSA ER	2009	
22N	MRSA Screening, A Positive Result N-ER	2009	
23E	No Excuses Making health and social services better ER	?	
23N	No Excuses Embrace partnership now N-ER	2006	
24E	Mental health in the future. What the Government is going to do ER	2011	
24N	No Health without Mental Health N-ER	2011	
25E	Our health, our care, our say ER	2006	
25N	Our health, our care, our say N-ER	2006	
26E	Working Together ER	?	
26N	Keys to partnership N-ER Executive Summary	2002	
27E	All about personal health budgets ER	2012	
27N	Understanding personal health budgets N-ER	2012	
28E	Staying positive: the Criminal Justice System and Learning Disabilities ER	2011	
28N	Positive Practice, positive outcomes N-ER	2011	
29E	Safeguarding adults. A consultation ER	2008	
29N	Safeguarding adults. A consultation N-ER	2008	
30E	Smoke Free England ER	?	No digital version on website
30N	Smoke Free England N-ER	?	
31E	Swine flu jab ER	2010	
31N	Swine flu vaccination N-ER	2009	
32E	Valuing Employment Now ER	2009	
32N	Valuing Employment Now N-ER Executive Summary	2009	

33E	Valuing People Now. (VPN) A new three year strategy ER	2010	
33N	Valuing People Now (VPN). A new three year strategy N-ER	2010	
34E	Valuing People and Research The Learning Disability Research Initiative ER	2007	
34N	Valuing People and Research The Learning Disability Research Initiative N-ER	2007	
35E	Valuing People Annual 2004 ER		Years don't match but shown together on website
35N	Valuing People Annual 2005 N-ER		
36E	VPN Summary report ER	2009	
36N	VPN Summary report N-ER	2009	
37E	Valuing People Planning ER	2002	Accessible Document incomplete
37N	Valuing People Planning N-ER	2001	
38E	Valuing People Story so Far ER	2005	No mainstream comparator
38N	Valuing People Story so Far (N-ER??)	2005	
39E	VPN The Delivery Plan 2009-2010 ER	2009	Superseded by Delivery Plan 2010 2011
39N	VPN The Delivery Plan 2009-2010 N-ER	2008	
40E	VPN The Delivery Plan 2010-2011 ER	2010	
40N	VPN The Delivery Plan 2010-2011 N-ER	2010	
41E	Moving money for learning disabilities Social Care from the NHS to local councils ER	?	
41N	VPN Transfer of the responsibility for the commissioning of social care for adults with a learning disability from the NHS to local government N-ER	2008	
42E	An Information Revolution ER	2010	
42N	Liberating the NHS. An Information Revolution N-ER	2010	
43E	Winterbourne View review Concordat or Agreement,	?	

	Programme of Action ER				
43N	DH Winterbourne View review Concordat: Programme of Action N-ER	2012			
44E	Winterbourne View Final ER	?			
44N	Winterbourne View Final N-ER	2012			
45E	Caring for our future. Reforming care and support ER	2012			
45N	Caring for our future: reforming care and support N-ER	2012			
46E	Changing the way we plan training for healthcare staff ER	2010			
46N	Liberating the NHS. Developing the healthcare workforce N-ER	2010			
47E	Local Involvement Networks explained ER	2007		No section in m/s less than 1000 words	
47N	Getting ready for LINKs. Planning your local Involvement Network N-ER	2007			
48E	National Stroke Strategy ER	2008	Not designed specifically for ALD but for adults with aphasia by Connect.		
48N	National Stroke Strategy N-ER	2007			
	TOTAL pairs excluded		7	4	2
	TOTAL pairs included		41	37	35

Appendix Chapter 2. ii The Survey matched headings

		Sample No	1-7
42E Information Revolution	42M Information Revolution		
What do you think about our plans for health and social care services?	Executive summary		
Information for Everyone			
Why is this a good thing?			
A new information strategy			
An Information Revolution – the details	Chapter 1 – An information revolution	1	
Part 1 – New ways of working			
Part 2 - Information for patients, people who use services, carers and everyone else	Chapter 2 – Information for patients, service users, carers and the public	2	
Part 3 - Information about better services	Chapter 3 – Information for improved outcomes	3	
Part 4 – Information for staff	Chapter 4 – Information for professionals	4	
Part 5 - Using information so local hospitals and organisations can be more independent from government	Chapter 5 – Information for autonomy, accountability and democratic legitimacy	5	
Part 6 – The information strategy	Chapter 6 – Setting the direction – the information strategy	6	
Tell us what you think	The consultation process	7	
Private Information	An information revolution		
(Headings 7 Subheadings 6)	The challenge and the opportunity		
	How will the information revolution work?		
	Can we afford an information revolution?		
	Why the information revolution needs you		
	Information for patients, service users, carers and the public		
	Patient/ service user control of records		
	Why would patients and service users want control of their records?		
	What does patient and service user control of records mean?		
	What needs to happen to enable patients and service users to control their records?		

Appendix Chapter 2. iii The Survey Headings with no match

Document 11E Health Action Planning: excluded due to lack of matching content

		Sample No	1-3	Exclude? (Not enough matching)			
11E Health Action Planning	11M Health Action Planning						
Summary – what this guide says		1					
Introduction	1. Introduction	2					
What do these words mean?	Scope and purpose of this guidance						
Why we have written this guide	Level 1 – Service development work and informing planning and commissioning						
The important things to remember in making Health Services better	Level 2 – Person-to-person work with people with learning disabilities						
	Target audience						
	Headlines for commissioning bodies						
Ideas for making health action plans and facilitation happen	Supporting health action planning and health facilitation: headlines for strategic health authorities						
Quality	Leadership						
What is good health facilitation?	Data and knowledge management						
Health Facilitation	Commissioning to improve outcomes						
A good Strategic Health Facilitator should work like this and know these things	Engaging with people with learning disabilities and family carers						
A good personal facilitator worker should be someone like this	Working with community partners and collaborating with clinicians						
	Supporting health action planning and health facilitation: headlines for primary care trusts						
	Leadership						
	Data and knowledge management						
	Commissioning to improve outcomes						
	Engaging with people with learning disabilities and family carers						
	Working with community partners and collaborating with clinicians						
	Supporting health action planning and health facilitation: headlines for local authorities						

Document 12 E Healthcare for all:excluded due to lack of clear matching of titles

12E Healthcare for all	12M Healthcare for all	Exclude? No clear matching.		
Healthcare for all	Foreword			
What did we do?	Executive summary			
What did the Inquiry find out?	Recommendations			
(Headings 3 Subheadings 0)	Chapter 1: The nature of the problem			
	Introduction			
	Background			
	Prevalence			
	Health and behaviour			
	Treatment and care			
	Children			
	Issues for carers			
	Summary			
	Chapter 2: The national context			
	The legal framework			
	Disability Discrimination Act			
	Mental Capacity Act			
	The Carers Act			
	The framework for healthcare in the NHS			
	Healthcare providers			
	Primary care			
	Health policy			
	The Operating Framework			
	Learning disabilities policy			
	Summary			
	Chapter 3: Overcoming the barriers			
	Priority and profile			

Appendix Chapter 4. i Discourse Analysis Texts 1E and 1N

1E Referential Function

ER Text Questions to Ask when you go to the doctor or hospital

- 1 Ask your doctor or hospital for someone to support you **if** you want help at the doctor or hospital.
- 2 Ask a friend or family member to come with you, **if you like**. At the doctor or hospital don't be
- 3 afraid to ask **if** you don't understand. Say: "Can you say that again? I still don't understand." **If** you
- 4 don't understand any words, ask the doctor to explain them. You could ask the doctor to write down
- 5 any difficult words so you can look them up **later**. Write things down, or ask a family member or
- 6 friend to do this. **Before you leave** the doctor or hospital check that you have done everything on
- 7 your list, you know what should happen next, and **when it should happen**. Write it down.
- 8 Ask "Can I just check I understood what you said?", "Who should I ask if I have any more problems
- 9 or questions?"
- 10 Ask "Where can I get more information?", "Are there any support groups that could help me?", "Are
- 11 there any letters written about me? I would like to see copies of these."
- 12 **After you leave** the doctor or hospital write down what you talked about and what happens next.
- 13 Keep your notes. Book any tests that you can, and put the dates in your diary. **If** you do not hear
- 14 quickly about your next appointment, ask "What is happening?" **If** you don't get the results when
- 15 you expect them, ask "Can I have the results of my tests?" **If** it is not clear, ask "What do the results
- 16 of my tests mean?"

1N Referential Function

N-ER Text Questions to Ask

- 1 Write down your two or three most important questions.
- 2 List or bring all your medicines and pills – including vitamins and supplements.
- 3 Write down details of your symptoms, including **when they started and what makes them better or**
- 4 **worse**.
- 5 Ask your hospital or surgery for an interpreter or communication support **if needed**.
- 6 Ask a friend or family member to come with you, **if you like**.
- 7 **During** your appointment, don't be afraid to ask **if** you don't understand. For example, 'Can you say
- 8 that again? I still don't understand.' **If** you don't understand any words, ask for them to be written
- 9 down and explained. Write things down, **or** ask a family member or friend to take notes.
- 10 **Before you leave** your appointment check that you've covered everything on your list, you
- 11 understand, (for example 'Can I just check I understood what you said?'), you know what should
- 12 happen next and **when**.
- 13 Write it down. Ask who to contact **if** you have any more problems or questions about support
- 14 groups and **where** to go for reliable information, and for copies of letters written about you – you
- 15 are entitled to see these. **After your** appointment, don't forget:
- 16 Write down what you discussed and what happens next. Keep your notes. Book any tests that you
- 17 can and put the dates in your diary.

Analysis of Referential Function 1E and 1N Questions to Ask

Use of language to develop who is being represented in the texts, what they are doing and who is doing it are similar. Each text is aiming to deliver the same information.

Nouns, noun phrases refer to similar entities although 1E expands on these less than 1N. For example, 1N expands on the type of information that the reader might want to take with them to a hospital appointment (1N L 2, L 3) specifying 'medicine, pills, vitamin supplements, details of symptoms' whereas 1E only acknowledges that the reader might have personal information with them when it refers (1E/ L 7) to a 'list' that is not previously mentioned. Similarly 1N specifies that the reader might like 'communication support' or an 'interpreter' (1N/ L 5) as well as 'friend or family member' (1N/ L 6, L 9). In 1E, this is reduced to 'someone' (1E/ L1) and implies that this will be a 'friend or family member'.

For some reason, despite the title of the leaflet, the word 'appointment' is used only once in 1E in relation to a 'next appointment' but is used 3 times in 1N where all references are to the current appointment.

Information has been reduced in 1E compared to 1N.

Verbs /verb phrases in the both texts are dominated by the directive 'write (down)' and 'ask'. In 1N, 'write down' and 'ask' are each repeated 6 times. In 1E, 'ask' is repeated 11 times and 'write down' is only used 4 times. This reflects a stronger focus in the ER version on asking and a more equal focus in the N-ER version on both modalities of asking and writing down.

Both texts repeatedly use the negative phrase 'don't understand' implying the assumption that there will be difficulties for the reader in understanding things at this appointment. *This implies less expectation of people with IDs*

The use of '**if**' conditionally fronts several sentences in each document. In 1N (L 5, 7, 8, 13) these open up the options for the reader, providing choices in the following clauses of what might be done next or tagging the statement with a possibility of preference e.g. 'if you like', and 'if needed'. This is also the case in 1E/L 1 'if you like'. However the other 'ifs'(L 1, 2, 13, 14, 15) are all followed by a direct solution for the reader, telling him what to 'say' or 'ask'. The cluster of 'ifs' in the last two lines (L 13, 14, 15)of 1E state 3 negative outcomes in quick succession and what to do about them. This has the effect of leaving the reader with the overall impression that things will probably go wrong and goes against the positive title 'Making the most out of your appointment'. The last five lines in 1N (L 13-17) end on a more positive note, reminding the reader to write down the information discussed. Sentences here begin with direct verbs 'ask, write down, keep, book'. Words that orientate actions within time in relation to the appointment differ in the two texts. In 1E (L 6, 12) the reader is advised about what should take place 'before you leave' and 'after you leave'. They are also told to be alert 'about the next appointment'. In 1N, there is a clearer orientation through sequential use of 'during your appointment', 'before you leave your appointment' and 'after your appointment' (L 7, 10, 15).

'if' opens up negative conditions but closes them again in ER with a directive solution. Less negative in N-ER and provides options. Activities and actions are more clearly situated around the appt beg/middle/end in MS. Less clear in ER.

1E Interpersonal Function

ER Text Questions to Ask when you go to the doctor or hospital

- 1 Ask **you** doctor or hospital for someone to support **you if you want help** at the **doctor or hospital**.
- 2 Ask a friend or family member to come with **you**, if **you** like. At the doctor or hospital **don't be afraid**
- 3 **to ask** if **you don't understand**. Say: "Can **you** say that again? I still **don't understand**." If **you don't**
- 4 **understand** any words, ask the doctor to explain them. **You** could ask the doctor to write down any
- 5 **difficult** words so **you** can look them up later. Write things down, or ask a family member or friend to
- 6 do this. Before **you** leave the **doctor or hospital** check that **you** have done everything on **your** list,
- 7 **you** know what should happen next, and when it should happen. Write it down.
- 8 Ask "Can **I** just check **I** understood what **you** said?", "Who should **I** ask if **I** have any more **problems**
- 9 **or questions**?"
- 10 Ask "Where can **I** get more information?", "Are there any support groups that could help **me**?", "Are
- 11 there any letters written about **me**? **I would like to see copies of these**."
- 12 After **you** leave the **doctor or hospital** write down what **you talked about** and what happens next.
- 13 Keep **your** notes. Book any tests that **you** can, and put the dates in your diary. If **you** do not hear
- 14 **quickly** about **your** next appointment, ask "**What is happening**?" If you **don't get the results** when
- 15 **you** expect them, ask "Can **I** have the results of **my** tests?" If it is **not clear**, ask "What do the results
- 16 of **my** tests mean?"

1N Interpersonal Function

N-ER Text Questions to Ask

- 1 Write down **you** **two or three most important** questions.
- 2 **List or bring all your medicines** and pills – including vitamins and supplements.
- 3 Write down **details** of **your** symptoms, including **when they started** and what makes them **better or**
- 4 **worse**.
- 5 Ask your **hospital or surgery** for an interpreter or communication **support if needed**.
- 6 Ask a friend or family member to come with **you**, if **you** like.
- 7 During your **appointment**, **don't be afraid to ask if you don't understand**. For example, 'Can **you** say
- 8 that again? **I** still **don't understand**.' If you **don't understand** any words, ask for them to be written
- 9 down and explained. Write things down, or ask a family member or friend to take notes.
- 10 Before **you** leave **your** appointment check that **you've** covered everything on **your** list, **you**
- 11 understand, (for example 'Can **I** just check **I** understood what you said?'), **you** know what should
- 12 happen next and when.
- 13 Write it down. Ask who to contact if **you** have any more **problems or questions** about support
- 14 groups and where to go for **reliable** information, and for copies of letters written about **you – you**
- 15 **are entitled** to see these. After **your** appointment, **don't forget**:
- 16 Write down what **you discussed** and what happens next. Keep **your** notes. Book any tests that **you**
- 17 can and put the dates in **your** diary.

Analysis of Interpersonal function 1E and 1N Questions to Ask

The relationship between author and audience in these two texts is differently defined through **pronoun** use, **evaluative words and phrases** and the use of **modal verbs and phrases**. **Mood- imperative or declarative sentence/phrase** types

The author in both texts refers to the reader as 'you' indicating a personal voice from the author. 1N refers to the other main actor only once as 'hospital or surgery' (L 5) whereas 1E refers to the other main actor as the 'doctor or hospital' 4 times (L 1, 6, 12). This identifies a *person* in the form of a doctor in 1E, but only refers to locations in 1N or to the 'appointment' (L 7) creating a sense of distance in the N-ER version.

There is an assumption in both texts (through use of the repeated phrase 'don't understand' (1E/ L 3, 4; 1N/ L 7, 8) that the reader is likely to have difficulties understanding what is happening during the appointment. This is especially the case in 1E where it is combined with negatively loaded words and phrases and such as 'difficult words' (L 5) 'do not hear quickly' (L 13), 'don't get the results (L 14) and 'not clear' (L 15). Other phrases in 1E such as 'want help' (L 1), rather than 'support if needed' (L 5 in 1N), or 'ask: what is happening' (1E/ L 14)

These create an assumption that the reader needs help and direction. This is less obvious in 1N where the author has assumed that the information about 'wanting help' or asking 'what is happening' is not required. This focus on things being difficult and the reader needing help particularly in 1E is evidence of empathy in the author voice but perhaps over-empathy. It scaffolds the experience of the health appointment in 1E as negative rather than neutral or positive. The use of the adjective 'reliable' in 1N (L 14) in relation to information is not used in 1E where 'information' is not qualified by an adjective, allowing the impression that 'any' information is acceptable. The adjective 'reliable' might be a low frequency word and therefore more difficult to understand, however there are other qualifiers that would have been suitable such as 'useful' or 'good' in relation to information that are higher frequency and easier to understand. An adjective here provides the reader with more agency for deciding what information would be 'reliable' for them whereas no adjective reduces agency.

There is an assumption at the beginning of 1N that the reader will have 'important' questions to ask (L 1), will be responsible for knowing about their own medicines and also will have 'details' (L 3) of symptoms and as the expert in their own case will know what makes them better or worse. None of this expertise is attributed to the readers of the ER version (1E). They are advised at the beginning of the text to 'get help' and to find a friend or a family member to come along (L 2). Further evidence of the power differential in terms of agency occurs again near the end of the paragraph where the reader in 1N is reminded that they are 'entitled' to see any information written about them (L 15). In 1E, the reader is encouraged to ask (using a tentative modal construction) 'I would like to see copies of these' (L 11) with reference to information written about them. This removes the level of agency present in the word 'entitled' and implies that the reader with LD does not have the same right to see these documents as the reader of 1N.

1E Textual Function

ER Text Questions to Ask when you go to the doctor or hospital

- 1 **Ask your doctor or hospital** for someone to support you if you want help at the doctor or hospital.
- 2 **Ask a friend or family member** to come with you, if you like. **At the doctor or hospital** don't be
- 3 afraid to ask if you don't understand. Say: "Can you say that again? I still don't understand." If you
- 4 don't understand any words, **ask** the doctor to explain them. You could **ask** the doctor to write down
- 5 any difficult words so you can look them up later. Write things down, or **ask** a family member or
- 6 friend to do this. **Before you leave the doctor or hospital** check that you have done everything on
- 7 your list, you know what should happen next, and when it should happen. Write it down.
- 8 **Ask** "Can I just check I understood what you said?", "Who should I ask if I have any more problems
- 9 or questions?"
- 10 **Ask** "Where can I get more information?", "Are there any support groups that could help me?", "Are
- 11 there any letters written about me? I would like to see copies of these."
- 12 **After you leave the doctor or hospital** write down what you talked about and what happens next.
- 13 Keep your notes. Book any tests that you can, and put the dates in your diary. **If you do not hear**
- 14 **quickly about your next appointment, ask** "What is happening?" **If you don't get the results when**
- 15 **you expect them, ask** "Can I have the results of my tests?" **If it is not clear, ask** "What do the results
- 16 of my tests mean?"

1N Textual Function

N-ER Text Questions to Ask

- 1 **Write down your two or three most important questions.**
- 2 **List or bring** all your medicines and pills – including vitamins and supplements.
- 3 **Write down** details of your symptoms, including when they started and what makes them better or
- 4 worse.
- 5 **Ask** your hospital or surgery for an interpreter or communication support if needed.
- 6 **Ask a friend or family member** to come with you, if you like.
- 7 **During your appointment,** don't be afraid to ask if you don't understand. For example, 'Can you say
- 8 that again? I still don't understand.' If you don't understand any words, **ask** for them to be written
- 9 down and explained. Write things down, or **ask** a family member or friend to take notes.
- 10 **Before you leave your appointment** check that you've covered everything on your list, you
- 11 understand, (for example 'Can I just check I understood what you said?'), you know what should
- 12 happen next and when.
- 13 Write it down. **Ask** who to contact if you have any more problems or questions about support groups
- 14 and where to go for reliable information, and for copies of letters written about you – you are
- 15 entitled to see these. **After your appointment,** don't forget:
- 16 Write down what you discussed and what happens next. Keep your notes. Book any tests that you
- 17 can and put the dates in your diary.

Analysis of Textual function 1E and 1N Questions to Ask

Both texts serve to inform the reader. In this sense they serve the same purpose. However, the **links that help the reader** to progress through the texts to make sense of the content are distinct. This function takes textual cohesion into account (patterns of words, chains of related words, thematic linking and staging of words for effect), as well as overall coherence which is related to shared contextual knowledge and reaches outside the text itself.

The textual cohesion in 1N is scaffolded more clearly with a beginning, middle and end for the reader (as mentioned in relation to referential function). There is an implication in the activities outlined in the first two sentences that these are preparatory (L 1, 2, 3). They provide instructions to 'write down important questions' (L 1), 'list or bring medicines and pills' (L 2) and to 'write down symptom' information (L 3). These are directed to the reader who is then invited to 'ask a family member' to join them (L 5). The other sign posts in this text (1N) use prepositional phrases to indicate progression, as in 'during your appointment' (L 7), then 'before you leave' (L 10) and finally 'after your appointment' (L 15).

1E uses less signposting and does not include any instructions implicit or explicit for preparatory information. Instead it starts by inviting the reader to look for 'a friend or family member' to accompany them (L 2). This moves very quickly into being 'at the' doctor (L 2), where the focus is still on things that the reader does not 'understand' (L 3, 4). It then moves to 'before you leave the doctor' (L 6) and to 'after you leave the doctor' (L 12). The similarity of the construction of these two phrases apart from 'before' and 'after' to indicate a point in time are easy to confuse as they are both related to 'leaving the doctor' which is also an ambiguous concept.

There are further examples of how time is referenced in this text (1E). The first mention of an 'appointment' comes at the end of the paragraph in 1E, by referring to the 'next appointment' (L 14). This then moves the information away from the current theme, time and place (being at the doctor) onto another imagined theme (test results) (L 14, 15), at a time and place in the future. It requires more shared contextual knowledge of how appointments and test results are managed. The N-ER text (1N) does not require the reader to make this contextual temporal leap into the future, but finishes with advice about what to do immediately after the end of the current appointment 'After your appointment, don't forget:' (L 15).

Both texts are informative but 1N provides better linguistic cohesion and requires less cognitive demands in terms of overall coherence.

Appendix Chapter 4. ii Discourse Analysis Texts 2E and 2N

2E Referential Function

ER Text Personal Health Budget

- 1 You **must spend** the **money** on **things** in your **care plan** that **keep** you **healthy and safe**.
- 2 The **local NHS** **has to agree** that these **things** **support** your **health**. **If things are working well at the**
- 3 **moment**, you **do not have to change** them. But a **personal health budget** means you **can change**
- 4 **things if you want to**.
- 5 We **think personal health budgets** **could work** in 3 ways:
- 6 **Notional budget**: We **tell** you **how much money** there is for your **care**. You **say how you want** us to
- 7 **spend the money**. **If** your **local NHS team** **agrees** this **meets** your **needs** they **arrange** the **care and**
- 8 **support** for you.
- 9 **Real budget held** by a **third party**: An **organisation, like a charity**, **looks after** the **money for you** and
- 10 **helps you decide how you want** to **spend** it. They are called the **third party**. **If** the **local NHS** **agrees**
- 11 with **how you want** to **spend** your **money**, the **organisation** **buys** the **care and support for you**.
- 12 **Direct payment for healthcare**: We **give** you the **money** to **buy and manage** your own **healthcare**
- 13 **and support**. Your **local NHS team** **must agree** that this **meets** your **needs**. You **have to tell** us **what**
- 14 you **spend** the **money** on. You **can already have** a **notional budget** or **real budget held** by a **third**
- 15 **party**. We **are testing out** **direct payments** in **certain places** in **England**.

2N Referential Function

N-ER Text Personal Health Budget

- 1 A **personal health budget** is an amount of **money to support** your **individual healthcare and**
- 2 **wellbeing needs, planned and agreed between you** or your **representative** and your **local NHS**
- 3 **team**.
- 4 **At the centre** of your **personal health budget** is your **care plan**. This **plan helps you decide** your
- 5 **health and wellbeing goals, together with** the **local NHS team** who **support** you, and **set out** how
- 6 your **budget** will be **spent** to **enable** you to **reach** them and keep healthy and safe.
- 7 **If** you have a **personal health budget**, you **will be able** to use it for a **range of things** to **help you**
- 8 **meet** your **goals, for example** **therapies, personal care and equipment**. You **will not be able to pay**
- 9 for **emergency care** and **care you normally get from a family doctor**. You are also **not allowed to**
- 10 **spend** the money on **gambling, debt repayment, alcohol or tobacco, or anything unlawful**.
- 11 You **don't have to change** the **healthcare and support that is working well for you, but if** there's
- 12 **something that isn't working**, you **can change** that.
- 13 We think **personal health budgets** **could work** in three ways, **or a combination of them**:
- 14 1. **Notional budget**. No **money changes hands**. You **find out how much** money **is available** and **talk**
- 15 **to** your **local NHS team** **about** the different ways to **spend** that money on **meeting your needs**. They
- 16 **will then arrange** the **agreed care and support**.
- 17 2. **Real budget held by a third party**. A **different organisation or trust** holds the **money** for you and
- 18 **helps you decide** what you need. After you **have agreed** this with your **local NHS team**, the
- 19 organisation then **buys** the **care and support** you have **chosen**.
- 20 3. **Direct payment for healthcare**. You **get** the **cash to buy** the **care and support** you and your **local**
- 21 **NHS team** **decide** you need. You **have to show** what you **have spent** it on, but you, or your
- 22 **representative, buy and manage services yourself**.
- 23 Options 1 and 2 **are possible** now. **Direct payments for healthcare** **are being tested** in **some areas of**
- 24 **England**.

Analysis of Referential Function 2E and 2N Personal Health Budget

Use of language to develop who is being represented in the texts, what they are doing and who is doing it are distinct. The use of **nouns, noun phrases** and **verbs /verb phrases** and adverbs/ prepositional phrases/ words indicating **time and place / circumstance**

The main **noun** 'personal health budget' is the topic of the text and is used in both 2E and 2N but it is elaborated, described and evaluated differently through use of other nouns and noun phrases. 2E describes it as 'money' to be used for 'things' in a 'care plan' (L 1) and go on to inform the reader 'we tell you how much money there is' (L 6), whereas in 2N, it is described as an 'amount of money' linked to the terms 'planned and agreed' between the reader and the NHS (L 1), indicating that the amount is established by an actor outside the context of the text, to be used specifically for 'individual wellbeing and healthcare needs' (L 1). 2N goes on to place the 'care plan' within this 'personal health budget' (L 4) by using the term 'at the centre' (L 4), suggesting an abstract entity that can be visualised based on an individual's 'goals' as the focus (L 5, 8). The concept of 'goals' for care are broken down into a list using nouns that provide specific information about what the money can be used for ('therapies, personal care and equipment' (L 8)) and cannot be used for ('emergency care and care you normally get from a family doctor', 'gambling, debt repayment, alcohol or tobacco, anything unlawful' (L 10). In contrast, 2E gives little detail about what the money can be used for, repeatedly using similar terms: 'care plan' (L 1), 'health' (L 2), 'care' (L 6), 'care and support' (L 7, 8), 'healthcare' (L 12), 'healthcare and support' (L 12, 13) and using the generic term 'things' 4 times (L 1, 2, 4) to refer to what the money might be used for. Both 2E and 2N differentiate the 3 terms 'notional budget', 'real budget' and 'direct payments'.

The descriptions in 2E do not provide clear differences. Each one refers to the provision of either: 'care and support' (L 7 under Notional budget and L9 under Real budget) or 'healthcare and support (L 12 under Direct payments) all of which are under the control of the 'NHS team' conditionally (L 7, 10) or as an imperative (L13). The three provisions are more clearly differentiated in 2N through defining what happens to the money following each heading: 'Notional Budget: No money changes hands' (L 14), 'Real budget held by a third party: A different organisation or trust holds the money' (L 17) and 'Direct payment for healthcare: You get the cash...' (L 20). There is also more agency given to the reader here than in 2E, evident in the verbs and adjectives used: 'NHS *arranges agreed* care and support' (Notional) (L 16) , A third party '*holds*' and '*buys*' care and support for you '*agreed with... NHS*' (Real budget) (L 17, 19) and 'you *get* the cash to *buy* care and support you and your local NHS team *decide* you need' '*buy and manage services...yourself*' (Direct payments) (L 20, 21). In 2E, the notional budget category does not link the money with any agency, only to the author 'we tell you how much money there is' (L 6). To the reader it is not clear who 'we' is. The real budget links the money to an 'organisation, like a charity' (L 9) and the direct payments link the money directly to the reader 'we give you the money' (L 12).

In 2N, the spending is organised around 'goals' (L 5, 8) and is 'planned and agreed' (L 2) 'between' (L 2) or 'together with the NHS team' (L 5) who will 'support' the decisions (L 5). Other verbs such as 'set out (goals) (L 5), 'to enable' (L 6), 'will be able' (L 7) and 'to help you meet (your goals) (L 7) suggest a joint focus on a process of planning, goal-setting and discussion. The term 'goal' is not evident in 2E. Instead, the word 'needs' is used (L 7, 13). 'For you' is used twice (L 9, 11) in place of 'together with' (L 5) and 'between' (L 1) which are used in the N-ER version.

Also in 2E, 'How much' money (L 6) is spent and 'how you want' (L 4, 6, 10, 11) to spend it is qualified by the following **phrase** 'Your local NHS has to/ must agree' which is used twice in this text (L 2, 13), and then used with the **conditional** 'if the local NHS agrees' also twice; once at the beginning (L 7) and then in relation to the types of budget described (L 10). This suggests in 2E that the final decision/ locus of control lies with the NHS regardless of what the reader wants or says and has the effect of further reducing the joint decision-making process that is represented in 2N through use of **noun phrases** 'meeting your needs' (L 15), 'agreed care and support' (L 16), 'care and support you have chosen' (L 19) and 'care and support you and your local NHS team decide you need' (L 20). The joint agency represented in 2N is further supported by examples of the use of **verb phrases** '*talk to* [your local NHS team]' (L 14), they '*will then arrange*' (L 16), [the organisation] '*helps you decide*' (L 18), and 'you *have agreed* [this with your local NHS team]' (L 18).

2E Interpersonal Function

ER Text Personal Health Budget

- 1 **You must** spend the money on things in **your** care plan that keep **you** healthy and safe.
- 2 The local NHS **has to** agree that these things support your health. **If** things are working well at the
- 3 moment, **you do not have to** change them. But a personal health budget means **you can** change
- 4 things **if you** want to.
- 5 **We** think personal health budgets could work in 3 ways:
- 6 Notional budget: **We tell you how much money there is** for **your** care. **You say how you want us to**
- 7 **spend** the money. **If your** local NHS team agrees this meets your needs **they** arrange the care and
- 8 support **for you**.
- 9 Real budget held by a third party: An organisation, like a charity, looks after the money **for you** and
- 10 **helps you** decide how you want to spend it. They are called the third party. **If** the local NHS agrees
- 11 with how **you** want to spend **your** money, the organisation buys the care and support **for you**.
- 12 Direct payment for healthcare: **We give you** the money to buy and manage **your** own healthcare and
- 13 support. **Your** local NHS team **must** agree that this meets **your** needs. **You have to tell us** what **you**
- 14 spend the money on. **You can** already have a notional budget or real budget held by a third party.
- 15 **We** are testing out direct payments in certain places in England.

2N Interpersonal Function

N-ER Text Personal Health Budget

- 1 A personal health budget is an amount of money to support **your** individual healthcare and wellbeing
- 2 needs, planned and agreed between **you** or **your** representative and your local NHS team.
- 3 At the centre of **your** personal health budget is **your** care plan. This plan helps **you** decide your
- 4 health and wellbeing goals, together with the local NHS team who support **you**, and set out how your
- 5 budget will be spent to enable **you** to reach them and keep healthy and safe.
- 6 If you have a personal health budget, **you will be able** to use it for **a range** of things to help **you** meet
- 7 **your** goals, for example therapies, personal care and equipment. **You will not be able** to pay for
- 8 emergency care and care **you** normally get from a family doctor. **You** are also not allowed to spend
- 9 the money on gambling, debt repayment, alcohol or tobacco, or anything unlawful.
- 10 **You don't have to** change the healthcare and support that is working well for **you**, but if there's
- 11 something that isn't working, **you can** change that.
- 12 **We** think personal health budgets **could** work in three ways, **or a combination** of them:
- 13 1. Notional budget. No money **changes hands**. **You** find out how much money is available and talk to
- 14 **your** local NHS team about the **different ways** to spend that money on meeting **your** needs. **They** will
- 15 then arrange the agreed care and support.
- 16 2. Real budget held by a third party. A **different** organisation or trust holds the money for **you** and
- 17 helps **you** decide what **you** need. After **you** have agreed this with **your** local NHS team, the
- 18 organisation then buys the care and support **you** have chosen.
- 19 3. Direct payment for healthcare. **You** get the **cash** to buy the care and support **you** and **your** local
- 20 NHS team decide you need. **You** have to show what **you** have spent it on, but **you**, or **your**
- 21 representative, buy and manage services **yourself**.
- 22 Options 1 and 2 are possible now. Direct payments for healthcare are being tested in some areas of
- 23 England.

Analysis of Interpersonal function 2E and 2N Personal Health Budget

The relationship between author and audience in these two texts is differently defined through **pronoun** use, **evaluative words and phrases** and the use of **modal verbs and phrases**. Also through **imperative or declarative** sets mood. Also how words are used to address, include and exclude the reader or others

It is not clear who the personal pronoun 'we' (L 5, 6, 12, 15) refers to in 2E. It appears to be a self-identified middle man (author) that suggests another layer of control between the reader and the NHS which is given clear full control (see previous interpersonal function section). This extra layer or intermediary is not evident in 2N.

The auxiliary verb 'must' (L 1, 13) and 'have to' (L 2, 13) imply obligation and certainty: 'you must spend' (L 1) 'NHS has to/must agree' (L 2, 13), 'you have to tell us' (L 13). Combined with directives 'we tell you' (L 6) 'you say how you want us.' (L 6) 'we give you' (L 12) 'we think' (L 5) and prepositional 'for you' (L 8, 9, 11) where something is 'being done for' the person with LD all suggest a relationship between 'you and us' where the power is located with the 'us' and the 'we' of the author rather than with the reader. There are no instances in 2N where 'for you' is used in this way. There is also no mention of the middle man 'we' or 'us' in 2N and the relationship of the author is more neutral, outlining only a working relationship 'between' the reader and the NHS where decisions are taken 'together'.

Use of **modals** such as 'can' (L 11) and 'could' (L 12) and positive constructions 'will be able' (L 6) are all used in 2N and only twice (L3, 14) in 2E. The effects of possibility and uncertainty conveyed by modals in 2E is overridden by the strong use of directives ('you must spend' (L1), 'we tell you' (L 6), 'we give you' (L 12), 'you have to tell us' (L 13). In 2N, direct language is further softened by the use of **evaluative words** that suggest choice and option: a 'range of things' (L 6), 'or a combination of them' (L 12) and 'different ways' to spend the money (L 14).

The imposition of power is very strong in 2E where **interrogatives and imperatives** frame the interaction between reader and author, compared to 2N where the source of the imposition ('we') is not referred to.

2E Textual Function

ER Text Personal Health Budget

- 1 You must spend the **money** on **things** in **your care plan** that keep you **healthy and safe**.
- 2 **The local NHS** has to agree that **these things** support your **health**. **If things are working well at the**
- 3 **moment**, you do not have to change **them**. But a **personal health budget** means you can change
- 4 **things** if you want to.
- 5 We think **personal health budgets** could work in 3 ways:
- 6 **Notional budget:** We tell you how much **money** there is for your care. You say how you want us to
- 7 spend the **money**. **If your local NHS team** agrees this meets your **needs** they arrange the **care and**
- 8 **support** for you.
- 9 **Real budget held by a third party:** **An organisation, like a charity**, looks after the **money** for you and
- 10 helps you decide how you want to spend it. They are called the **third party**. **If the local NHS agrees**
- 11 with how you want to spend your **money**, the organisation buys **the care and support** for you.
- 12 **Direct payment for healthcare:** We give you **the money** to buy and manage your own **healthcare**
- 13 **and support**. Your **local NHS team** must agree that **this** meets **your needs**. You have to tell us what
- 14 you spend **the money** on. You can already have a **notional budget** or **real budget** held by a **third**
- 15 **party**. We are testing out **direct payments** in certain places in England.

2N Textual Function

N-ER Text Personal Health Budget

- 1 A **personal health budget** is an **amount of money** to **support your individual healthcare** and
- 2 **wellbeing** needs, planned and agreed between you or your representative and your **local NHS** team.
- 3 **At the centre of your personal health budget** is your **care plan**. **This plan** helps you decide your
- 4 health and wellbeing goals, together with the local NHS team who support you, and set out how your
- 5 budget will be spent to enable you to reach them and keep healthy and safe.
- 6 **If** you have a **personal health budget**, you will be able to use it for a range of things to help you meet
- 7 your goals, **for example** therapies, personal care and equipment. You will not be able to pay for
- 8 emergency care and care you normally get from a family doctor. You are also not allowed to spend
- 9 the money on gambling, debt repayment, alcohol or tobacco, or anything unlawful.
- 10 You don't have to **change** the **healthcare and support** that is working well for you, but **if** there's
- 11 **something that isn't working**, you can **change that**.
- 12 We think **personal health budgets** could work in three ways, or a combination of them:
- 13 1. **Notional budget.** No money changes hands. **You find out** how much money is available and **talk to**
- 14 **your local NHS team** about the different ways to spend **that money** on meeting your needs. **They**
- 15 will then arrange the agreed care and support.
- 16 2. **Real budget** held by a **third party**. A **different organisation or trust** holds the money for you and
- 17 helps you decide what you need. After you have agreed this with your local NHS team, the
- 18 organisation then buys **the care and support you have chosen**.
- 19 3. **Direct payment for healthcare.** **You get the cash** to buy **the care and support you and your local**
- 20 **NHS team decide you need**. You have to show what you have spent it on, but **you, or your**
- 21 **representative, buy and manage services yourself**.
- 22 **Options 1 and 2 are possible now. Direct payments for healthcare are being tested in some areas of**
- 23 **England**.

Analysis of Textual function 2E and 2N Personal Health Budget

Both texts serve to inform the reader. In this sense they serve the same purpose. However, the **links that help the reader** to progress through the texts to make sense of the content are distinct.

Both are informational texts. 2N provides far more detail than 2E using 'for example' (L 7) and then expanding the information. Information given in 2E is much more limited and restricted with no examples. Instead, it depends on repetition of terms to provide links. There is a high level of noun co-reference.

'Things' is repeated 4 times (L 1, 2, 4) and is referred back to once with the pronoun 'them' (L 3). 2N starts by defining the 'personal health budget' and then introduces the care plan situated 'at the centre' of the budget providing a conceptual visual frame of reference. It then defines the 'plan', what it is for and how it will work. The plan is further developed through a list of examples of what can and cannot be included. Finally, the reader is reminded that they do not have to change anything if they do not want to. There is less co-reference in 2N compared to 2E particularly with respect to noun repetition, however 2N does provide more depth in terms of content and more layers of information through the conventions of defining terms followed through with examples. This gives better overall coherence to the text.

2E begins by stating that money 'must be' spent to keep the reader 'healthy and safe' (L 1), and then qualifies this by saying that it will happen only if the NHS 'agree' (L 2). It then states that 'if things are working well at the moment, you do not have to change them...But...you can change things if you want to' (L 3). The flow of this information is stilted by a lack of cohesion in these 3 messages. Initially it is imperative that money is spent. Then control is removed by the presence of the NHS and in the third sentence some control is given back through reassuring the reader that nothing has to change.

Both the texts are divided under 3 separate headings 'notional budget', 'real budget' and 'direct payments' and both texts provide a short description of each one. In 2E, the repetition of words 'money', 'budget', 'third party' and 'organisation' make differentiating between these three types of budget difficult. There is little elaboration of the terms. Conceptually they reinforce through repeated use of terms the ideas that money must be spent on health care and support if the NHS agrees. Little extra information is given and the coherence of the text is further hindered by use of the intrusive author pronoun 'we' when it is not clear who this player is. The overall coherence of the text sample is less than evidenced in 2N. The three headings in 2N show better progression through use of linguistic cohesion mechanisms. Starting with the 'notional budget', this is described as 'no money changes hands' (L 13) immediately identifying that money is there but not given to anyone. Again, there is an amount available and spending it will be agreed between the reader and the NHS. No 'we' is used in this text. In the second budget type (real budget), the phrase '*different organisation or trust*' is used (L 16) suggesting to the reader that this money is held by someone other than the NHS (as the only previous organisation to be mentioned thereby allowing the reader to differentiate between them). Finally, with the direct payment budget, the first phrase is 'you get the cash...' (L 19) leaving the reader in no doubt about who has the money compared to the previous two budget types. By using co-reference that is not simply noun repetition, 2N is much less ambiguous. There is a further example of this in the final two sentences in 2E which are ambiguous: 'You can already have a notional budget or real budget held by a third party. We are testing out direct payments in certain places in England.' (L 14, 15). It is not clear which budget is held by the third party, nor is it clear how 'direct payments' relates to this. Use of the adverb 'already' is too weak to link the previous information with these final sentences. In contrast, the final two sentences in 2N (providing the same information) are shorter and clearer (L 22). It uses references to the numbered budget options 1 and 2 to achieve this, and then refers to option 3 by repeating the heading used in the sentence above 'direct payment for healthcare' (L 22).

Appendix Chapter 4. iii Discourse Analysis Texts 3E and 3N

3E Referential Function

ER Text Caring for our future

- 1 **Care and support** means lots of different **things** for different **people**.
- 2 It **depends** on what each **person** needs, but can **include** things like **help** to **get out of bed**, **get**
- 3 **dressed** or **washed**, **eating** or **cooking** meals, **help** with **seeing friends and family**, **caring** for **others**.
- 4 We all **know** **someone** who **needs** **care and support**, and **most people** will **need** some **care and**
- 5 **support** themselves **at some time in their lives**.
- 6 **Care and support** comes from lots of different **people**; **family**, **friends**, **people** in the **community**.
- 7 **Depending on** how much **money** **people** have, the Government **helps** to **pay** for some **parts** of **care**
- 8 **and support**.
- 9 This **White Paper** is for **people** who are 18 or older, the **people** who **work** in **care and support**, **family**
- 10 **carers** and **others** who **care** for **someone**

3N Referential Function

N-ER Text Caring for our future

- 1 **Care and support** enables **people** to do the **everyday things** that most of us take for granted: things
- 2 like **getting out of bed**, **dressed** and **into work**; **cooking** meals; **seeing friends**; **caring** for our **families**;
- 3 and **being part** of our **communities**. It might **include** **emotional support** at **a time of difficulty or**
- 4 **stress**, or **helping people** who are **caring** for a **family member** or **friend**. It can mean **support** from
- 5 **community groups** and **networks**: for example, **giving others** a lift to a **social event**.
- 6 It might also **include** **state-funded support**, such as **information and advice**, **support** for carers,
- 7 **housing support**, **disability benefits** and **adult social care**. **Care and support** is something that
- 8 **affects** us all: 76 per cent of **older people** will **need** **care and support** at **some point in later life**. We
- 9 will all know **someone**, a **family member or friend**, who **needs** some **extra care or support** to lead a
- 10 **full and active life**.

Analysis of Referential function 3E and 3N Caring for our future

Use of language to develop who is being represented in the texts, what they are doing and who is doing it are distinct. Despite each text aiming to deliver the same information, the use of **nouns, noun phrases** and **verbs /verb phrases** in 3E represent a more restricted concept of both 'support' and 'care'. Ultimately the language used is less inclusive of the audience and more directive. Both documents begin with the words 'Care and support...' (L 1 in each), clearly stating the same theme. 3N then uses the verb 'enables' (L 1) which implies inclusive support, whereas 3E uses 'means' (L 1) which implies that a definition of 'care and support' will follow. The definition in the form of a noun phrase 'lots of different things for different people' (L 1) uses non-specified vocabulary and as a result carries much less meaning than its comparator in 3N where the active verb 'to do' (L 1) is used along with a clear description of what people 'do': 'the everyday things that most of us take for granted' (L 1).

Similarly, 3N mentions 'being part of communities' (L 3) whereas in 3E, 'people in the community' (L 6) are placed as the actors in the place where care and support 'come from' (L 6), creating a clear divide between the 'community' and those who receive care and support. 3N expands on the kinds of varied support available using nouns (L 6) 'advice and information', 'disability benefit', 'adult social care' and adjectives such as 'emotional', 'state funded' and 'housing' to describe support. The implication is that this is available to all. **When and how** 'support' will happen is also indicated in both texts, but is less specified in 3E. In 3E, the main reference to state care and support is 'Depending on how much money people have, the Government helps to pay for some parts [of it]' (L 7). This turns support and care into something restricted, available only to some, and decided by the authorities in relation to a person's financial situation.

The final sentence in 3N uses the phrase 'to lead a full and active life' (L 9). Use of the verb 'to lead' is active, implies independence and freedom, and the adjectives to describe 'life' as 'full' and 'active' are progressive and further emphasise the concepts of participation, activity and wellbeing. The final sentence in text 3E is less outwardly focused and is restrictive in comparison to 3N. It reduces the text to a summary of 'This White Paper' (L 9), identifying who it has been written for 'people who are 18 or older, the people who work in care and support, family carers and others who care for someone'. The information in this sentence gives a list of who the audience is, but does not summarise what the paper is trying to say or how support might expand and improve someone's future life as described in 3N.

'...others who care for someone' (L 10) is another example of highly non-specific and therefore ambiguous information. The word 'help' is used 3 times in 3E but only used in 3N once suggesting less agency in the former case.

3E Interpersonal Function

ER Text Caring for our future

- 1 Care and support means lots of different things for different **people**.
- 2 It **depends** on what each person needs, but **can** include things like help to get out of bed, get dressed
- 3 or washed, eating or cooking meals, help with seeing friends and family, caring for others.
- 4 **We all** know someone who **needs** care and support, and most people will need some care and
- 5 support **themselves** at some time in **their** lives.
- 6 Care and support comes from lots of different **people**; family, friends, people in the community.
- 7 **Depending on** how much money **people** have, the Government helps to pay for some parts of care
- 8 and support.
- 9 This White Paper is for **people** who are 18 or older, the people who work in care and support, family
- 10 carers and others who care for someone.

3N Interpersonal Function

N-ER Text Caring for our future

- 1 Care and support enables **people** to do the everyday things that most of **us** take for granted: things
- 2 like getting out of bed, dressed and into work; cooking meals; seeing friends; caring for **our** families;
- 3 and being part of **our** communities. It **might** include emotional support at a time of difficulty or
- 4 stress, or helping **people** who are caring for a family member or friend. It **can** mean support from
- 5 community groups and networks: **for example**, giving others a lift to a social event.
- 6 It **might** also include state-funded support, such as information and advice, support for carers,
- 7 housing support, disability benefits and adult social care.
- 8 Care and support is something that affects **us all**: 76 per cent of older **people** will need care and
- 9 support at some point in later life. **We will all** know someone, a family member or friend, who needs
- 10 some extra care or support to lead a full and active life.

Analysis of Interpersonal function 3E and 3N Caring for our future

The relationship between author and audience in these two texts is differently defined through **pronoun** use, **evaluative words and phrases** and the use of **modal verbs**.

Primarily, the author refers to 'we' and 'us' and 'our' 5 times (L 1, 3, 8, 9) in total in 3N and only once in 3E (L4). Most references to the other actors in both texts are to generic 'people' (3E/ L 1, 4, 6, 7; 3N/ L 1, 4, 8) with more repetition of this in 3E than in 3N.

Third person pronouns, not evident in 3N are used in 3E: 'themselves' and 'their' (L 5). This has the effect of creating a 'them and us' distance between author and reader in 3E whereas the author is including himself together with the reader in 3N by using 'we' and 'us' more frequently. This suggests that the attitude of the author in 3N is more inclusive. In 3E, the author has separated himself from the audience and is speaking to them as a spokesperson or as someone in authority. Furthermore, the use of the words 'needs' (L 4), and 'depending' (L 7) in 3E imply that the reader or the 'other' is in a weaker position than the author. These words are not used in 3N where instead there is a more inclusive mention of 'community groups and networks' (L 5) which are not used in 3E where reference is made only to 'people in the community' (L 6).

Use of modal verbs can be an expression of uncertainty and in 3N, they are used 3 times in tentative exploration of the kinds of support and care that we might need e.g. 'can mean' (L 4) and 'might include' (L 3, 6). This implies that the author is accounting for the fact that as individuals, he cannot draw boundaries or make rules about 'us'. The modal verb 'can' (L 2) is used only once in 3E suggesting less uncertainty. 'For example' (L5) is also used in 3N but not in 3E, and supports the voice of uncertainty or possibility for the reader.

3E Textual Function

ER Text Caring for our future

- 1 **Care and support** means lots of different things for different people.
- 2 It depends on what each person needs, but can include things like help to get out of bed, get dressed
- 3 or washed, eating or cooking meals, help with seeing friends and family, caring for others.
- 4 We all know someone who needs **care and support**, and most people will need some **care and**
- 5 **support** themselves at some time in their lives.
- 6 **Care and support** comes from lots of different people; family, friends, people in the community.
- 7 Depending on how much money people have, the Government helps to pay for some parts of **care**
- 8 **and support**.
- 9 **This White Paper** is for people who are 18 or older, the people who work **in care and support**, family
- 10 carers and others who care for someone

3N Textual Function

N-ER Text Caring for our future

- 1 **Care and support** enables people to do the everyday things that most of us take for granted: things
- 2 like getting out of bed, dressed and into work; cooking meals; seeing friends; **caring** for our families;
- 3 and being part of our communities. It might include emotional **support** at a time of difficulty or
- 4 stress, or helping people who are **caring** for a family member or friend. It can mean **support** from
- 5 community groups and networks: for example, giving others a lift to a social event.
- 6 It might also include state-funded **support**, such as information and advice, **support** for carers,
- 7 housing **support**, disability benefits and adult social **care**.
- 8 **Care and support** is something that affects us all: 76 per cent of older people will need **care and**
- 9 **support** at some point in later life. We will all know someone, a family member or friend, who needs
- 10 some extra **care or support** to lead a full and active life.

Analysis of Textual function 3E and 3N Caring for our future

Both texts serve to inform the reader. In this sense they serve the same purpose. However, the links that help the reader to progress through the texts to make sense of the content are distinct. The terms 'care and support' (L 1) are the first words in both texts and are repeated as a phrase three times in 3N, all at the end (L 8, 10). This allows the reader to refer back to the previous explanations and examples of 'care and support' that have been given throughout the text. 'Care' (as separate from 'support') and words related to it (carer, caring) are used 3 times in 3N (L 2, 4, 7) and the word 'support' on its own is repeated 5 times (L 3, 4, 6) in the body of the text, demonstrating how text 3N expands around a discussion of separate constructs of 'care' and 'support'. In 3E, however, the full term 'care and support' is repeated 5 times after the initial introduction of the theme (L 1, 4, 6, 7, 9). 'Support' is not used as a separate term in the text and 'caring / care /carers' is repeated 3 times (L 3, 10).

While repetition of the full phrase 'care and support' in 3E should provide the reader with prompts to refer back to prior information, there is little content about 'care and support' in the text to refer back to. The two terms are divided in 3N and further examples given, leading finally to 'a full and active life' (L 10). In 3E the information defining 'care and support' is limited to 'help to get out of bed, get dressed or washed, eating or cooking meals, help with seeing friends and family' (L 3). In 3E the theme of 'care and support' is less well developed than in 3N. This is not only evident in the repetitive use of the phrase 'care and support' but in the number of times the author uses non-specific language such as 'people' (L 1, 4, 6, 7, 9), 'others' (L 3, 10), 'someone' (L 4, 10), and 'different' (L 1, 6) in relation to 'care and support' without elaboration or examples. The 'conclusion' states only who the paper is for in 3E (L 9) but does not refer or summarise the content. This creates weak textual cohesion and less progression in 3E compared to 3N. In the N-ER version, the theme is stated at the beginning, the terms divided and explained, and finally the theme reiterated along with a positive summarising conclusion.

Overall, Text 3N provides a wider scope and an inclusive focus with a natural progressive elaboration of information whereas 3E is limited and excluding with superficial repetition

Appendix Chapter 4. iv Discourse Analysis Texts 4E and 4N

4E Referential Function

ER Text VPN The Delivery Plan 10 11

- 1 Valuing Employment Now aims to increase the number of people with learning disabilities in paid work by
- 2 2025.
- 3 In 2010/2011, Government departments and agencies will work together to deliver the commitments
- 4 made in Valuing Employment Now.
- 5 The cross-Government team will support the Getting a Life Programme and make sure that best practice
- 6 about ways into employment for young people are shared.
- 7 The cross-Government team will support the new Project Search sites and share best practice.
- 8 The cross-Government team will support the new Employment project for people with complex needs.
- 9 The cross-Government team will work with people with learning disabilities and family carers across the
- 10 country to raise aspirations about getting a paid job.

4N Referential Function

N-ER Text VPN The Delivery Plan 10 11

- 1 Having a real, paid job that you enjoy is the best route to a full life. If we are serious about equality for
- 2 people with learning disabilities, employment must be a top priority. Real jobs make people better off
- 3 financially, as well as growing people's confidence, social life and improving health. However, the first
- 4 national data on employment for people with learning disabilities showed the employment rate to be
- 5 even lower than expected, at just 7.5%.
- 6 Valuing Employment Now aims to radically increase this by 2025, especially for people with moderate and
- 7 severe learning disabilities who have been left behind the furthest. As many as possible of these jobs
- 8 should be 16 hours or more per week, because this is when people will be financially better off and will
- 9 achieve greater social inclusion. The aspiration in Valuing Employment Now is to close the gap between
- 10 the employment rate of people with moderate and severe learning disabilities and that of disabled
- 11 population as a whole, which in today's terms would mean 48% of people with moderate and severe
- 12 learning disabilities in work.
- 13 We know that young people are much more likely to get a real job after school or college if they have had
- 14 meaningful work experience and support from a supported employment provider from age 14,
- 15 underpinned by person-centred planning and reviews. Research also shows the importance of parents
- 16 and carers who view employment as a positive and possible option for the young person. These factors
- 17 can be built into a comprehensive transition pathway, which will lead to employment for young people
- 18 with learning disabilities when they leave school or college.
- 19 In 2010/2011, DH, DWP, DCSF, BIS, ODi, Department for transport, Lifelong Learning UK, Jobcentre Plus
- 20 and the cabinet Office will deliver the commitments made in Valuing Employment Now. The priorities for
- 21 the cross-government valuing Employment Now team in this year will be: work with the Getting a Life
- 22 demonstration sites to publish and implement the pathway to employment for young people locally,
- 23 share good practice regionally and report to government on the remaining barriers to young people going
- 24 into jobs and getting full lives; support the new Project search sites to go live in September 2010 and lead
- 25 a full evaluation; support the work of the sustainable Hub for innovative employment for people with
- 26 complex needs; work with the Jobs First sites to demonstrate and evaluate how personal budgets can be
- 27 used for employment; set national targets and milestones for Valuing Employment Now in line with the
- 28 baseline set by PSA 16 in July 2009 and subject to future priorities in the next spending review; develop
- 29 and publish national standards for supported employment and job coaching, and work with BIS and the
- 30 appropriate sector skills councils to develop job coach qualifications; add to the Valuing Employment Now
- 31 resource hub in line with feedback from regions and local areas; work with people with learning
- 32 disabilities and family carers across the country to promote the aspiration and expectation of
- 33 employment; Progression through Partnership will be updated and a delivery plan will be published
- 34 setting out actions for national implementation.
- 35 It is essential that the public sector leads by example in recruiting people with learning disabilities.
- 36 Thirteen Government Departments are committed to developing policies and procedures that will lead to
- 37 the recruitment of people with learning disabilities throughout the civil service. A similar commitment is
- 38 in train within the NHS, beginning with a project that will target ten trusts throughout England.

Use of language to develop who is being represented in the texts (entities and participants), what they are doing (processes) and who is doing it., where, when, how and why (circumstance) through the use of **nouns, noun phrases** and **verbs /verb phrases** and **adverbial, prepositional phrases** in each text.

4N is full of very long **noun phrases** that are extended into descriptive lists, in turn creating lengthy sentences. This is evident in the number of noun phrases highlighted compared to the number of **verbs and verb phrases** or **adverbial and prepositional** phrases highlighted. 4E shows the same pattern with a heavy load of nouns and noun phrases compared to verbs or adverbs but the overall length of 4E is only around 7 lines of text compared to 4N which is 26 lines long.

The variation of actors/participants (noun phrases) used in 4E is limited. 'Cross government Team' (as the main actor is repeated at beginning of 4 out of the 6 sentences (L 5, 7, 8, 9) and these link with verbs 'aims to increase' (L 1) 'will support' (L 5, 7, 8), 'will work' (L 9), 'will work...to deliver' (L 3) 'share' (L 6), 'make sure' (L 5) and 'getting' (L 10) to represent direct relational processes with 'Valuing Employment Now' (L1), 'Getting a Life Programme' (L 5), 'the cross-Government team' (L 5, 7, 8, 9), 'Project Search sites' (L 7) the 'Employment project' (L 8) and 'people with learning disabilities' (L 9) in 4E. It is assumed that the reader will be familiar with these projects and services. Similarly, it is assumed that readers will be aware of the meaning of 'best practice about ways into employment' (L 5). Both the 'cross government team' and those elements they are link with are generic and abstract entities.

The same representations can be tracked in 4N. As mentioned, the number of nouns and noun phrases is very high and large sections of the text read like a long list of policy-orientated procedures that will be carried out by 'Valuing Employment Now' (L 6, 9) and later by 'DH, DWP, DCSF, BIS, ODi, Department for Transport, Lifelong Learning UK, Jobcentre Plus and the cabinet Office' (L 19). The government will 'deliver' (L 20), 'publish and implement' (L 22), 'share' (L 23), 'support' (L 24, 25,), 'lead' (L 24), 'demonstrate and evaluate' (L 26), 'develop'(L 28), 'work with' (L 21, 26, 31) and 'add to' (L 30) and 'promote' (L 32) a variety of aspects relating to jobs and employment for people with learning disabilities. Examples of these aspects are 'priorities' (L 20) and 'good practice' (L 23), 'barriers' (L 23), 'national targets and milestones' (L 27, 28), 'delivery plans' (L 33), 'action for national implementation' (L 24) and 'policies and procedures' (L 36). This use of [government participants-active verb-abstract entity] reflects a text that is made up of a high level of material processes, possibly typical of government information generally. These processes are similar in both texts although 4N carries a lot more detail. Statistical evidence e.g. '[the number of] employed young people with learning disabilities is at 7.5%' (L 5) is also presented providing more circumstantial reference in 4N that is not apparent in 4E. Use of verb phrases referring to the future also provide circumstantial reference in both texts. However, there is a much bigger range of verbs used in 4N than in 4E e.g. 'to develop' (L 28, 30), 'add to' (L 30), 'promote' (L 32), 'will be updated' (L 33), 'will be published' (L 33), 'will lead to' (L 33), and 'will target' (L 36). 4E repeats 'will support' (L 7, 8, 9) three times and 'will work' twice (L 3, 9) in a text of only 10 lines.

4E Interpersonal Function

ER Text VPN The Delivery Plan 10 11

- 1 Valuing Employment Now aims to increase the number of **people with learning disabilities** in paid work
- 2 by 2025.
- 3 In 2010/2011, Government departments and agencies will work together to deliver the commitments
- 4 made in Valuing Employment Now.
- 5 The cross-Government team **will support** the Getting a Life Programme and **make sure** that best practice
- 6 about ways into employment for **young people** are shared.
- 7 The cross-Government team **will support** the new Project Search sites and share best practice.
- 8 The cross-Government team **will support** the new Employment project for **people with complex needs**.
- 9 The cross-Government team **will work** with **people with learning disabilities and family carers** across the
- 10 country to raise aspirations about getting a paid job.

4N Interpersonal Function

N-ER Text VPN The Delivery Plan 10 11

- 1 Having a **real, paid** job that **you** enjoy is the **best** route to a full life. If **we** are serious about equality for
- 2 people with learning disabilities, employment **must** be a **top** priority. **Real** jobs make **people** better off
- 3 financially, as well as growing **people's** confidence, social life and improving health. However, the first
- 4 national data on employment for **people with learning disabilities** showed the employment rate to be
- 5 **even lower than expected**, at just 7.5%.
- 6 Valuing Employment Now aims to **radically increase** this by 2025, especially for **people with moderate**
- 7 **and severe learning disabilities** who **have been left behind the furthest**. **As many as possible** of these
- 8 jobs should be 16 hours or more per week, because this is when **people will be** financially better off and
- 9 **will achieve** greater social inclusion. The aspiration in Valuing Employment Now is to close the gap
- 10 between the employment rate of **people with moderate and severe learning disabilities** and that of
- 11 disabled population as a whole, which in today's terms would mean 48% of **people with moderate and**
- 12 **severe learning disabilities** in work.
- 13 **We** know that **young people** are much more likely to get a real job after school or college if they have had
- 14 **meaningful** work experience and support from a supported employment provider from age 14,
- 15 underpinned by person-centred planning and reviews. Research also shows the importance of parents
- 16 and carers who view employment as a **positive and possible** option for the young person. These factors
- 17 **can** be built into a **comprehensive** transition pathway, which **will lead** to employment for young **people**
- 18 **with learning disabilities** when they leave school or college.
- 19 In 2010/2011, DH, DWP, DCSF, BIS, ODi, Department for transport, Lifelong Learning UK, Jobcentre Plus
- 20 and the cabinet Office **will deliver** the commitments made in Valuing Employment Now. The **priorities** for
- 21 the cross-government valuing Employment Now team in this year **will be**: work with the Getting a Life
- 22 demonstration sites to publish and implement the pathway to employment for young people locally,
- 23 share good practice regionally and report to government on the remaining barriers to young people going
- 24 into jobs and getting full lives; support the new Project search sites to go live in September 2010 and lead
- 25 a **full** evaluation; support the work of the **sustainable** Hub for **innovative** employment for **people with**
- 26 **complex needs**; work with the Jobs First sites to demonstrate and evaluate how personal budgets can be
- 27 used for employment; set national targets and milestones for Valuing Employment Now in line with the
- 28 baseline set by PSA 16 in July 2009 and subject to future priorities in the next spending review; develop
- 29 and publish national standards for supported employment and job coaching, and work with BIS and the
- 30 appropriate sector skills councils to develop job coach qualifications; add to the Valuing Employment Now
- 31 resource hub in line with feedback from regions and local areas; work with **people with learning**
- 32 **disabilities** and family carers across the country to promote the **aspiration and expectation** of
- 33 employment; Progression through Partnership will be updated and a delivery plan **will be** published
- 34 setting out actions for national implementation.
- 35 It is **essential** that the public sector leads by example in recruiting **people with learning disabilities**.
- 36 Thirteen Government Departments are committed to developing policies and procedures that **will lead** to
- 37 the recruitment of **people with learning disabilities** throughout the civil service. A similar commitment is
- 38 in train within the NHS, beginning with a project that **will target** ten trusts throughout England.

The relationship between author and audience in these two texts is differently defined through **pronoun** use, **evaluative words and phrases** and the use of **modal verbs and phrases**.

Mood- imperative or declarative.

4E is written in the **passive voice**, removing it from a direct voice to the reader. 4N is also written mostly in the passive voice, but there is some attempt at the beginning of the text where the author uses the familiar terms 'you' and 'we' (L1) and again towards the middle where 'we' is used (L 13). These could be in place of the generic 'one' ie. everyman, but it is not clear if this is the author's intention. Both versions refer to 'people with learning disabilities /complex needs' (4E/ L 1, 8, 9; 4N/ L 4, 17, 25, 31, 35, 37) and 'young people' (4E/ L 6; 4N/ L 13). 4N also refers three times to 'people with moderate and severe learning disabilities' (L 6, 10, 11). The use of both 'you' (as a generic term) (L 1) and 'we' (L 1, 13) while referring separately to 'people with learning disabilities' in 4N implies that the reader is neither young, nor someone with learning disabilities. 4E Does not use first or second person creating a more formal distance between author and reader.

There is only one example of use of a **modal verb** in 4N, 'can' (L 17) and none in 4E. Where other modals might have been used, **declaratives** 'will achieve' (4N/ L 9), will support (4E/ L 5, 7, 8), will work (4E/ L 9), will lead (4N/ L 20)' are evidenced in both texts. Only one auxiliary verb of obligation 'must' is used (L 2) in 4N, in relation to the government. Overall, 4N is written using certain voice for purposes of positive persuasion and security about the new employment policy. The language sets a positive, certain mood. The **evaluative words and phrases** identified in 4N similarly suggest something positive and promising for the future e.g. 'meaningful (L 14), positive and possible (L 16), comprehensive (L 17), priorities (L 20), sustainable (L 25), innovative (L 25), aspiration and expectation (L 32), essential' (L 35). The intensifier 'radically' (L 6) and other similar examples of qualifiers '**top** priority' (L 2) and '**even** lower than expected' (L 5) add weight to the content and imply importance and urgency. While both texts are written with declaratives, no evaluative words have been used in 4E suggesting that there is no need (or no room) to be persuasive at the ER level or to positively communicate the urgency of this policy.

4E Textual Function

ER Text VPN The Delivery Plan 10 11

- 1 **Valuing Employment Now** aims to increase the number of **people with learning disabilities in paid work**
- 2 **by 2025.**
- 3 In 2010/2011, **Government departments and agencies** will work together to deliver the commitments
- 4 made in **Valuing Employment Now.**
- 5 The cross-Government team will support the Getting a Life Programme and make sure that best practice
- 6 about ways into **employment** for young people are shared.
- 7 **The cross-Government team** will support the new Project Search sites and share best practice.
- 8 **The cross-Government team** will support the new **Employment** project for **people with complex needs.**
- 9 **The cross-Government team** will work with **people with learning disabilities and family carers** across the
- 10 country to raise aspirations about getting a **paid job.**

4N Textual Function

N-ER Text VPN The Delivery Plan 10 11

- 1 Having a **real, paid job** that you enjoy is the best route to a full life. If we are serious about equality for
- 2 people with learning disabilities, employment must be a top priority. **Real jobs** make people **better off**
- 3 **financially**, as well as growing people's confidence, social life and improving health. However, **the first**
- 4 national data on employment for people with learning disabilities showed the employment rate to be
- 5 even lower than expected, at just **7.5%.**
- 6 Valuing Employment Now aims to radically **increase this** by 2025, especially for people with moderate and
- 7 severe learning disabilities who have been left behind the furthest. As many as possible of **these jobs**
- 8 should be 16 hours or more per week, because this is when people will **be financially better off** and will
- 9 achieve greater social inclusion. **The aspiration in Valuing Employment Now is to close the gap between**
- 10 **the employment rate of people with moderate and severe learning disabilities and that of disabled**
- 11 **population as a whole, which in today's terms would mean 48% of people with moderate and severe**
- 12 **learning disabilities in work.**
- 13 We know that young people are much more likely to get a **real job** after school or college **if they have had**
- 14 **meaningful work experience and support from a supported employment provider from age 14,**
- 15 **underpinned by person-centred planning and reviews.** Research also shows **the importance of parents**
- 16 **and carers who view employment as a positive and possible option for the young person. These factors**
- 17 can be built into a comprehensive transition pathway, which will lead to employment for young people
- 18 with learning disabilities when they leave school or college.
- 19 In 2010/2011, **DH, DWP, DCSF, BIS, ODi, Department for transport, Lifelong Learning UK, Jobcentre Plus**
- 20 **and the cabinet Office will deliver the commitments made in Valuing Employment Now.** The priorities
- 21 for the **cross-government valuing Employment Now team** in this year will be: **work with the Getting a**
- 22 **Life demonstration sites to publish and implement the pathway to employment for young people**
- 23 **locally, share good practice regionally and report to government on the remaining barriers to young**
- 24 **people going into jobs and getting full lives; support the new Project search sites to go live in**
- 25 **September 2010 and lead a full evaluation; support the work of the sustainable Hub for innovative**
- 26 **employment for people with complex needs; work with the Jobs First sites to demonstrate and**
- 27 **evaluate how personal budgets can be used for employment; set national targets and milestones for**
- 28 **Valuing Employment Now in line with the baseline set by PSA 16 in July 2009 and subject to future**
- 29 **priorities in the next spending review; develop and publish national standards for supported**
- 30 **employment and job coaching, and work with BIS and the appropriate sector skills councils to develop**
- 31 **job coach qualifications; add to the Valuing Employment Now resource hub in line with feedback from**
- 32 **regions and local areas; work with people with learning disabilities and family carers across the country**
- 33 **to promote the aspiration and expectation of employment; Progression through Partnership will be**
- 34 **updated and a delivery plan will be published setting out actions for national implementation.**
- 35 It is essential that the public sector leads by example in **recruiting people with learning disabilities.**
- 36 Thirteen Government Departments are committed to developing policies and procedures that will lead to
- 37 the recruitment of people with learning disabilities throughout the civil service. A similar commitment is
- 38 in train within the NHS, **beginning with a project that will target ten trusts** throughout England.

Analysis of Textual function 4E and 4N VPN The Delivery Plan 10-11

Both texts serve to inform the reader. In this sense they serve the same purpose. However, the **links that help the reader** to progress through the texts to make sense of the content are distinct.

4E is highly repetitive and there is therefore little flow of new information throughout the text. There is a high level of noun co-reference in terms of repetition, and this has the effect of closing down any expansion of information. No definitions or descriptions of terms are given and there is little cohesion or coherence to the piece.

Despite the opaque nature of the entities represented (as identified through the referential function) 4N does use language and co-reference to progress throughout the text. 4N starts with a short definition of 'real jobs' (L 1) and then refers back to this (L 2). The idea is expanded with an outline of current levels of employment amongst people with learning difficulties using data and examples. A description of what is meant by 'real jobs' then follows a summary of the aims of the Valuing Employment Now policy. The next paragraph (L 13) refers to 'real jobs' again and gives a list of the factors that are likely to lead to one. There is a breakdown of the members of the 'cross government Valuing Employment Now team' (L 19) and a list of their priorities makes up the bulk of the rest of the text. The final paragraph (L 35) concludes with a statement about the first steps to be taken by the team (recruitment of people with learning disabilities) to reach these goals. There is a much clearer level of linguistic cohesion in 4N than in 4E and better textual coherence. Although 4N depends on a level of shared cognitive understanding, it also provides definitions and explanations and expands on ideas and concepts which are simply assumed in 4E.

Appendix Chapter 4. v Discourse Analysis Texts 5E and 5N

5E Referential Function

ER Text Valuing People and Research

1 **Our Health, Our Care, Our Say** said the **Government** would work with the **Disability Rights Commission**
2 on deciding on the **best services**. This is called 'commissioning'. In **Chapter 1** we told you how **people**
3 **were involved in deciding what research to give money to**. **People** were involved in saying what
4 **research** was good and **deciding who got the money**.
5 One of the **Valuing People research projects** involved **researchers with a learning disability**. They visited
6 the **12 research projects** to see how they had involved **people with learning disabilities** in their **research**.
7 The **researchers** found that all the **research projects** had used **people with learning disabilities** as **experts**
8 **in many ways**: as **advisers** and **on management groups**, **collecting information**, **making sense of the**
9 **data**, **supporting other people with learning disabilities** to be involved in the **research**, **writing reports**.
10 **Some projects** involved **people** more than others. But **more people with learning disabilities** are
11 **involved in research than ever before**. **Things** that could help in getting **people with learning disabilities**
12 **involved in research**: **rules for writing research ideas**, doing **research and reports in easy words and**
13 **pictures**, **other accessible formats and different forms such as plays**, making sure **support matches the**
14 **jobs people with learning disabilities have to do as researchers**, recognising **the costs of involving**
15 **people with learning disabilities in research** and **the cost** to them, **understanding and recognising the**
16 **value of different forms of knowledge**, knowing how to make **the research** help both **researchers** and
17 **those they research** without **the research** having a **bad effect** on either **group**.

5N Referential Function

Valuing People and Research

1 The **LDRI** was a **bold initiative** in **promoting** an **inclusive approach** to **research commissioning** and
2 **research management**. **Researchers** were invited to think about how they might **embrace inclusive**
3 **principles** but **were left to gauge how far these were 'fit for purpose'**. A team of **people with learning**
4 **disabilities** was expressly **commissioned to assess the experiences** of the remaining 12 studies in
5 **involving people with learning disabilities** in the **research process**. The **LMI** study **describes the findings**.
6 **The LDRI** has demonstrated that **people with learning disabilities can play important roles** in
7 **commissioning research**. For the future, **challenges** are likely to include the following: **developing**
8 **standards by which to judge inclusive research proposals**; **customising** the **support needs** of **service user**
9 **research commissioners**; **addressing** the ethical issues faced by **service user** peer reviewers; **ensuring**
10 **that service users are involved** in the pre-commissioning stages in **helping to design research tenders**. **In**
11 **relation to service user** involvement in managing the **research programme**, attention **should focus on**:
12 **publishing** better guidance for **research contractors** about the requirements and standards for easy-read
13 **research proposals** and final reports; the intellectual, logistical and economic factors involved in
14 producing easy-read **research outputs**, tied to an appreciation of the rationale and goals of knowledge
15 **dissemination and utilisation**; further **exploration and evaluation** of the potential for more creative
16 methods of **research dissemination** through performance arts, and their effects in **transforming** people's
17 views and behaviours; **service user involvement** in **research governance**, which is useful in continuous
18 testing of how emergent evidence is going to benefit the **service user** community and policy.
19 **The LMI study** contributed **evidence** about the **opportunities and challenges** of **engaging people with**
20 **learning disabilities** in **the remaining 12 LDRI studies**. It **showed** that there is **a need to think about** who
21 **funds** pre-protocol work undertaken by **service users**; the **economic and non-economic costs** to **service**
22 **users of becoming involved in research** in different roles; ethical challenges that can and do arise in
23 **inclusive research**, so that their effects **can be mitigated** or their chances of occurring **can be avoided**
24 altogether; the added value of **inclusive research**, requiring some assessment of different types of
25 knowledge and of standards or frameworks for assessing these different types of knowledge. This is a very
26 **challenging agenda**, and **one upon which much rests**; **a code of good practice for inclusive research**,
27 based on a recognition of the different contributions **people with learning disabilities** are making to
28 **research**.

Analysis of Referential function 5E and 5N Valuing People and Research

Use of language to develop who is being represented in the texts, what they are doing and who is doing it are distinct. Despite each text aiming to deliver the same information, the use of **nouns, noun phrases (to represent participants and entities – who, who, what)** and **verbs /verb phrases** in representation of processes (doing, happening, being, feeling thinking). **Verbs used as part of noun phrases...** Also circumstance (when, where, how) indicated by use of **adverbial and prepositional phrases**.

In 5N (28 lines of text), the main participants are represented by 'people with learning disabilities' (used 5 times: L 3, 5, 6, 19, 27) and 'service user' (used 7 times: L 8, 9, 10, 11, 17, 18, 21). In 5E, the same participants are represented through 'researchers with a learning disability' (L 5) which is used once and 'people with learning disabilities' (L 6, 7, 9, 10, 11, 14, 15) which is used 7 times. 'Service user' is not a term that is used in the easy read version where the text is shorter, with only 17 lines. More specific reference to 'people with learning disabilities' in the easy read version suggests a stronger focus on people with learning disabilities than in 5N, which generalises to 'service user'. There is an expectation that the reader understands that people with LDs are also the service users referred to in this context. (Along with the absence of the use of first and second person pronoun in 5N, this supports the assertion that the document is not speaking directly to the LDs population. See more in 'interpersonal function').

'Research' is identified as the central process taking place and the term is used frequently in both 5N and 5E, however it is limited to the simple form 'research' (L 3, 4, 6, 9, 11, 12, 15, 16, 19) or 'researchers' (L 7, 14, 16) in 5E and also 'research ideas' (L 12) and 'research projects' (L 6). By contrast in 5N, it is almost always presented as a compound noun. 'Research' is extended with 'commissioning' (L 1), 'management' (L 2), 'process' (L 5), 'proposals' (L 8,13), 'commissioners' (L 9), 'tenders' (L 10), 'programme' (L 11), 'outputs' (L 14), 'dissemination' (L16), and 'governance' (L17). The term 'inclusive' in relation to 'research' (L 8, 23, 24, 26) 'approaches'(L1) and 'principles' (L2) is used 6 times in 5N but is not used at all in 5E. The concept of 'research' in 5E compared to 5N is limited and narrow. Use of the term without the extra information communicated through adjectives (as in 5N) means that understanding the text relies on the reader already having a wide understanding of what the abstract concept 'research' entails.

The value of the research itself as expressed in 5N is given much stronger emphasis through use of these compound nouns than 'people with learning disabilities' who are mentioned less. 'Research' and the 'study' forefront the clause structure in 5N leaving the participants as secondary. 5E has a different focus – the repetition of 'people with learning disabilities' and the construction of clauses with them as central indicates more emphasis on the value they bring to the research rather than on the research process and outcomes.

Verb use also differs, particularly in the range of verbs used. How participants are represented in these processes is also reflected in the use of 'involved' which is repeated 8 times in the 5E (L 3, 5, 6, 9, 10, 12) and only used 3 times in 5N (L 5, 10, 22). In 5N many other verbs and verb phrases expand the idea of involvement: 'promoted' (L 1), 'invited to think' (L 2), 'commissioned to assess' (L 4), 'describe' (L 5), 'demonstrate' (L 6), 'judge' (L 8), 'customising' (L 8) 'develop' (L 7), 'include' (L 7), 'ensuring' (L 9), 'helping' (L 10), 'engage' (L 19), 'contributed' (L 19), 'mitigated' (L 23), 'avoided' (L 23) but mainly from the perspective of the 'researcher' or the research rather than people with learning disabilities. The other verbs used in 5E 'work' (L 1), 'decide' (L 2, 3, 4) 'visited' (L 5), 'found' (L 7), 'used' (L 7), 'collect' (L 8), 'make sense' (L 8), 'supporting' (L 9), 'writing'(L 9), 'making sure' (L 13), 'matching' (L 13), 'understanding' (L 15), 'recognising'(L 15), 'knowing how'(L 16) are more concrete verbs that are easier to visualise. Moreover, they are active verbs and the participation of people with learning disabilities in 5E is reinforced through this representation. The verbs used in 5N which are more abstract and lower frequency are less active and represent less active participation.

Prepositional phrases in 5N 'how far these were 'fit for purpose' (L 3), 'by which to judge' (L 8), 'in relation to' (L 10) and 'on which much rests' (L 27) provide information about circumstance that is abstract and related to thought processes rather than to specific points in place and time. In contrast, prepositional phrases used in 5E are more concrete e.g. 'in many ways' (L 8), 'on management groups' (L 8), 'as advisers' (L 8) 'as experts'(L 7) 'in easy words and pictures' (L 12), and 'as researchers' (L 14) framing processes that are more easily visualised in the real world.

5E Interpersonal Function

ER Text Valuing People and Research

1 Our Health, Our Care, Our Say **said** the Government **would** work with the Disability Rights Commission on
2 deciding on the **best** services. **This** is called 'commissioning'. In Chapter 1 **we** told **you** how people were
3 involved in deciding what research to give money to. **People** were involved in saying what research was
4 **good** and deciding who got the money.
5 One of the Valuing People research projects involved **researchers with a learning disability**. **They** visited
6 the 12 research projects to see how **they** had involved people with learning disabilities in their research.
7 The researchers found that all the research projects had used people with learning disabilities as experts
8 in many ways: as advisers and on management groups, collecting information, making sense of the data,
9 supporting other people with learning disabilities to be involved in the research, writing reports.
10 Some projects involved people more than **others**. But **more** people with learning disabilities are involved
11 in research **than ever before**. Things that **could** help in getting people with learning disabilities involved in
12 research: rules for writing research ideas, doing research and reports in easy words and pictures, other
13 accessible formats and different forms such as plays, making sure support matches the jobs people with
14 learning disabilities have to do as researchers, recognising the costs of involving people with learning
15 disabilities in research and the cost to **them**, understanding and recognising **the value** of different forms
16 of knowledge, knowing how to make the research help both researchers and those **they** research without
17 the research having a **bad** effect on **either group**.

5E Interpersonal Function

N-ER Text Valuing People and Research

1 The LDRI was a **bold** initiative in promoting an **inclusive** approach to research commissioning and research
2 management. **Researchers** were invited to think about how **they might embrace inclusive** principles but
3 were left to gauge how far these were 'fit for purpose'. A team of people with learning disabilities was
4 **expressly** commissioned to assess the experiences of the remaining 12 studies in involving people with
5 learning disabilities in the research process. The LMI study describes the findings. The LDRI has
6 demonstrated that people with learning disabilities **can** play **important** roles in commissioning research.
7 For the future, **challenges are likely** to include the following: developing standards by which to judge
8 **inclusive** research proposals; customising the support needs of service user research commissioners;
9 addressing the ethical issues faced by service user peer reviewers; ensuring that service users are involved
10 in the pre-commissioning stages in helping to design research tenders. In relation to service user
11 involvement in managing the research programme, attention **should** focus on: publishing **better** guidance
12 for research contractors about the requirements and standards for easy-read research proposals and final
13 reports; the intellectual, logistical and economic factors involved in producing easy-read research outputs,
14 tied to an appreciation of the rationale and goals of knowledge dissemination and utilisation; further
15 exploration and evaluation of the potential **for more creative** methods of research dissemination through
16 performance arts, and their effects in **transforming** people's views and behaviours; service user
17 involvement in research governance, which is **useful** in continuous testing of how **emergent** evidence **is**
18 **going to** benefit the service user community and policy.
19 The LMI **study** contributed evidence about the **opportunities and challenges** of engaging people with
20 learning disabilities in the remaining 12 LDRI studies. **It** showed that there is a need to think about who
21 funds pre-protocol work undertaken by service users; the economic and non-economic costs to service
22 users of becoming involved in research in different roles; ethical challenges that **can and do arise in**
23 **inclusive** research, so that their effects **can be** mitigated or their chances of occurring **can be** avoided
24 altogether; the **added value** of **inclusive** research, requiring some assessment of different types of
25 knowledge and of standards or frameworks for assessing these different types of knowledge. This is a
26 **very challenging agenda**, and **one upon which much rests**; a code of good practice for **inclusive** research,
27 based on a recognition of the different contributions people with learning disabilities are making to
28 research.

Analysis of Interpersonal function 5E and 5N Valuing People and Research

The relationship between author and audience in these two texts is differently defined through **pronoun** use, **evaluative words and phrases (loaded)** and the use of **modal verbs and phrases (uncertainty, or obligation), declarative, interrogative and imperative** clause type can signify mood. Also consider exclusion and inclusion of participants. Attitude

5N focuses more on the value of the research agenda identifying 'challenges' (L 7, 19) in the 'research process' (L 5), and less on 'people with learning disabilities' despite referring to them regularly in the text (see referential function). Both 5N and 34 E are written in **passive voice** the author is removed from the reader making reference to 'they' (5N/ L 2; 5E/ L 6, 16) and 'them' (5E/ L 15) (the researchers, including those with and without learning disabilities). This has the effect of distancing both reader and author from the actors referred to in the text. In 5N no other pronouns are used to refer to people, only to the research. 5E does use first person e.g. 'we told you' (L 2) and then shifts to referring to 'people /researchers with learning disabilities' as 'they' and 'them' throughout the rest of the text. This places the reader at the centre of the text but not necessarily directed to the reader as someone with learning disabilities.

There are no terms of obligation and certainty used in 5E. Use of 'should' (L 11) and 'is going to' (L 17) however, both suggest some **obligation and certainty** conveyed by the author in 5N. This is balanced with 6 examples of modal verbs: 'can' (L 6) 'might' (L 2) and 'likely to' (L 7) that suggest **uncertainty** in 5N, i.e. that the research focus in question is a work in progress and open to consideration and possible change. This suggests that the author in 5N is taking a balanced neutral stance, giving certainty but also leaving space for the reader to appreciate the future possibilities.

5E fronts the list of 'things that could help' (L11-17) with the modal 'could' allowing uncertainty and possibility to be conveyed to the reader throughout the last paragraph which constitutes about one third of the text. As a result of the long string of 'things' listed however, the conditional impact of 'could' in this case is weakened.

There are many **positive expressions of attitude** identified in 5N and these are mostly absent from 5E. Examples of these are 'bold [initiative] (L 1), inclusive (L 1,2,8,23,24,26), embrace (L2), expressly [commissioned] (L 4), important [roles] (L 6), better [guidance] (L 11), creative (L 15), transforming (L 16), useful (L 17), emergent (L 17), opportunities (L 19), added value (L 24), very challenging (L 26)'.

5E mentions 'best' [services] (L 1), '[what research was] good' (L 4), and towards the end of the text, refers to 'bad [effect]' (L 17). There is also reference to 'more [people] than ever before [are involved in research]' and 'the value [of different forms of knowledge]'. These are simple expressions of positive attitude on the part of the author and provide a less nuanced, more 'black and white' version of the positive expressions of attitude represented in 5N. They are also much fewer in number. The tone is more factual and language used is more concrete in 5E than in 5N with fewer adjectives. Most noticeable is the absence of the term 'inclusive' in 5E in relation to research.

5E Textual Function

ER Text Valuing People and Research

1 Our Health, Our Care, Our Say said the Government would work with the Disability Rights Commission on
2 deciding on the best services. **This** is called ‘commissioning’. In **Chapter 1** we told you how people were
3 involved in deciding what research to give money to. **People** were involved in saying what research was
4 good and deciding who got the money.

5 One of the **Valuing People research projects** involved **researchers** with a learning disability. **They** visited
6 the **12 research projects** to see how **they** had involved **people with learning disabilities** in their research.
7 **The researchers** found that all the **research projects** had used **people with learning disabilities** as experts
8 in many ways: as advisers and on management groups, collecting information, making sense of the data,
9 supporting other people with learning disabilities to be involved in the research, writing reports.

10 **Some projects** involved **people** more than others. But more **people with learning disabilities** are involved
11 in **research** than ever before. Things that could help in getting **people with learning disabilities** involved
12 in **research**: rules for writing **research ideas**, doing **research** and reports in easy words and pictures, other
13 accessible formats and different forms such as plays, making sure support matches the jobs **people with**
14 **learning disabilities** have to do as **researchers**, recognising the costs of involving **people with learning**
15 **disabilities** in **research** and the cost to **them**, understanding and recognising the value of different forms
16 of knowledge, knowing how to make the **research** help both **researchers** and **those they research** without
17 the **research** having a bad effect on **either group**.

5N Textual Function

N-ER Text Valuing People and Research

1 The **LDRI** was a bold initiative in promoting an inclusive approach to research commissioning and research
2 management. **Researchers** were invited to think about how they might embrace **inclusive principles** but
3 were left to gauge how far **these** were ‘fit for purpose’. **A team of people with learning disabilities** was
4 expressly commissioned to assess the experiences of the remaining 12 studies in involving people with
5 learning disabilities in the research process. **The LMI study** describes the findings. **The LDRI** has
6 demonstrated that **people with learning disabilities can play important roles in commissioning research**.

7 For the future, **challenges** are likely to include the following: developing standards by which to judge
8 inclusive research proposals; customising the support needs of service user research commissioners;
9 addressing the ethical issues faced by service user peer reviewers; ensuring that service users are involved
10 in the pre-commissioning stages in helping to design research tenders. In relation to **service user**
11 **involvement** in managing the research programme, attention should focus on: publishing better guidance
12 for research contractors about the requirements and standards for easy-read research proposals and final
13 reports; the intellectual, logistical and economic factors involved in producing easy-read research outputs,
14 tied to an appreciation of the rationale and goals of knowledge dissemination and utilisation; further
15 exploration and evaluation of the potential for more creative methods of research dissemination through
16 performance arts, and their effects in transforming people’s views and behaviours; service user
17 involvement in research governance, which is useful in continuous testing of how emergent evidence is
18 going to benefit the service user community and policy.

19 **The LMI study** contributed evidence about the opportunities and challenges of engaging people with
20 learning disabilities in the remaining **12 LDRI** studies. It showed that there is a need to think about who
21 funds pre-protocol work undertaken by service users; the economic and non-economic costs to service
22 users of becoming involved in research in different roles; ethical challenges that can and do arise in
23 inclusive research, so that their effects can be mitigated or their chances of occurring can be avoided
24 altogether; the added value of inclusive research, requiring some assessment of different types of
25 knowledge and of standards or frameworks for assessing these different types of knowledge. **This** is a very
26 challenging agenda, and **one upon** which much rests; a code of good practice for inclusive research,
27 based on a recognition of the different contributions people with learning disabilities are making to
28 research

Analysis of Textual function 5E and 5N Valuing People and Research

Both texts serve to inform the reader. In this sense they serve the same purpose. However, the **links that help the reader** to progress through the texts to make sense of the content are distinct.

5E introduces the text with 3 main entities 'Our Health, Our Care, Our Say', 'the Government' and 'the Disability Rights Commission' (L 1) by way of explaining 'commissioning' (L 2), but knowledge of these abstract bodies is assumed. There is no clear explanation for the reader of how these bodies make up the meaning of commissioning despite the statement that follows 'this is called commissioning' (L 2). None of these 3 entities, nor commissioning are referred to again in the text. The reader is also referred back to a point earlier in the document 'Chapter 1' (L 2) and there is an expectation that this will cue the reader into current information and terms. This requires shared information external to the current text. There follows a reference to 'people' (L 3) but the text does not specify who they are and the next sentence goes on to talk about 'the Valuing People Research Projects' (L 5) and 'researchers with a learning disability' (L 5). Reference is made twice to 'they' and once to 'their' in the following sentence (L 6) but it is ambiguous which actors (researchers or research projects) in the text they are specifically referring to or who the research belonged to. A list then follows (L 11-17) of ways in which people with learning disabilities had been used as 'experts' (L 7). This does link back to 'all the research projects' (L 7) identified in the previous line, but does not have a clear textual link with prior text.

Again, the generic term 'people' (L 10) is used in conjunction with 'some projects' (L 10) but this does not refer clearly back to the 'Valuing People Research Projects' (L 5) or 'people with learning disabilities' (L 7) mentioned before. The following sentence then states that many people with LDs are involved in research but again there are no cohesive elements that link this statement with the previous one apart from repetition of terms.

A list of how to get people with LD involved in research makes up the rest of the text (L 11-17). This creates a very long sentence and while it makes repeated reference to 'research' and 'researchers' (8 times), and to people with learning disabilities (twice), the repetition (co-reference) reduces/obscures the meaning of the sentence rather than providing useful signposting. It is not clear who 'them' (L 15) is in relation to cost, nor who 'either group' (L 17) refers to. Although technically, the text provides high lexical cohesion in the repetition of some words and phrases, the overall effect is to reduce coherence.

5N provides a much more sophisticated level of lexical cohesion through clearer use of co-reference that does not entail high levels of repetition and text structure overall provides good coherence. The text opens with a definition of the 'LDRI' (L 1), not assuming prior knowledge from the reader. The main players are then introduced (researchers and people with learning disabilities (L2 and 3) and outlines what they were tasked to do. A summary statement is then used that heads up the rest of the text for the reader 'The LDRI has demonstrated...' (L 5) stating the main finding. There follow three sections in this text (as in 5E) which are made up of long lists, first 'roles in commissioning research for people with LDs (L 5-11), secondly, service user involvement (L 10-18), and finally evidence from the LMI study (L 19-25). All three lists create long sentences, but unlike 5E, they are each clearly fronted with statements such as 'challenges are likely to include the following:' (L 7), 'attention should focus on:' (L 11) and 'it showed that...' (L 20). After the final summary of research and conclusion at end of the text (L 26-28), there is a closing sentence that refers the reader to the future, looking forward, using reference to the previous paragraphs with '**This** is a very challenging agenda...' (L 25). The distribution of information in 5N is logical and clear and for the proficient reader, it provides very good textual cohesion without over-repetitive noun co-reference of the type demonstrated in 5E. There is movement within the text but it is contained and does not expect the reader to have much shared outside knowledge from any other chapter, section or situation. As shown above, in contrast 5E does require more external knowledge.

Appendix Chapter 5. i – Ethical Approval



Health Research Authority
NRES Committee East Midlands - Northampton
The Old Chapel
Royal Standard Place
Nottingham
NG1 6PB

Telephone: 0115 883 9440

20 January 2014

Ms Susan E Buell
School of Rehabilitation Sciences
Queens Building 0.12
University of East Anglia
NR4 7TJ

Dear Ms Buell,

Study title:	The Easy Read Project. Participation in healthcare: an investigation into the accessibility value of health-based literature for people with poor literacy skills associated with intellectual disability
REC reference:	13/EM/0474
IRAS project ID:	133136

Thank you for your letter of 14 January 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, Rebecca Morledge, NRESCommittee.EastMidlands-Northampton@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rtforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

- *The Chair does make a suggestion for the Northampton Research Ethics Committee being named in the Participant Information Sheet rather than "an NHS Ethics committee". This can be submitted as a minor amendment.*

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 8 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering Letter		11 December 2013
Evidence of Insurance or Indemnity	Zurich	09 December 2013
Investigator CV		01 October 2013
Letter from Sponsor	University of East Anglia	09 December 2013
Other: CV - Karen Bunning		01 October 2013
Other: CV - Peter E Langdon		27 September 2013
Other: CV - Gabriela Pounds		
Other: Publicity leaflet	1	11 October 2013
Other: Definitions of Reading Comprehension	1	11 October 2013
Other: Reciprocal Reading Support Definitions	1	11 October 2013
Other: The Easy Read Task Texts, Scoring Information	1	11 October 2013
Other: The Easy Read Task Text A	1	11 October 2013
Other: The Easy Read Task Text B	1	11 October 2013
Other: Record sheet Text A		
Other: Record sheet Text B		
Other: Task explanation 'easy read' support sheet		
Other: Investigators scripts	1	11 October 2013
Other: Emails x 6 - confirming involvement		
Other: Recruitment form: Participants	2	08 January 2014
Participant Consent Form	1	11 October 2013
Participant Information Sheet	2	08 January 2014
Participant Information Sheet: Carers/Key Workers	1	08 January 2011
Protocol	1	11 October 2013
REC application	133136/539031/1/968	13 December 2013
Response to Request for Further Information		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/EM/0474	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely,



Mr Ken Willis
Chair

Email: NRESCommittee.EastMidlands-Northampton@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Yvonne Kirkham, University of East Anglia
Mr Paul Mills, Norfolk and Suffolk Primary and Community Care Research
Office*

Appendix Chapter 5. ii Ethical: considerations

This is a non-invasive study and participants will therefore be exposed to minimal risk throughout. All clients will be made aware through explanation and supporting visual material that they have the right to withdraw from the study at any time. This is stated in the information sheet and in the consent form and understanding will be checked by a person familiar to the participant.

Specific ethical issues for participants:

1. Maintaining confidentiality

Precautions taken: To maintain participant confidentiality, each one will be allocated a participant code by the principal investigator. This number will be used to identify all of the data collected in the study. This participant code will also be used to collate background information from the recruitment profile and the preparatory measures (BPVS and YARC assessments). Any data transferred to digital format will be done so only using the participant code. Susan Buell, the principal investigator is the only person to have access to the participants' names linking them to anonymised data.

All data managed in paper form and be kept on University premises in a master file within a locked filing cabinet. All audio data will be copied onto an encrypted memory stick within 8 hours of recording. They will then be transferred onto a secure facility at UEA which is password protected. All recordings will be identified digitally by participant number only and no names will be used.

2. Ensuring that adequate information is provided.

The participants in this study will have a range of cognitive abilities. Some could find the information provided more difficult to assimilate than others.

Precautions taken: Publicity leaflets, information sheets and consent forms have been designed in 'easy read' format, in collaboration with a volunteer advisory group from Opening Doors Advocacy Group in Norfolk. (Material scores reading ages of Grade 4- 6 on the Flesch Kincaid Readability measures. This reflects the reading ages found at the low end of the DoH 'easy read' material analysed in Stage 1.)

Once consent has been given with support from the gatekeeper, the participant will have a further opportunity to discuss the project with the investigator. A 'Total Communication Approach' will be used by the investigator to explain any issues arising and also to explain what is required of the participant. This involves using gesture, pictures from the information sheets, and showing the participant relevant assessment booklets and materials.

3. Coercion

It might be possible that participants feel coerced into taking part.

Precautions taken: Staff who are familiar with potential participants will have first generated a list of names based on knowledge of service users in collaboration with key workers, support workers and /or family members of those who fulfil the criteria for participation. They will be required to fill in a recruitment profile (Appendix B) for each person which helps to clarify these criteria. Participants will be initially approached by staff members who know them well and who work with them. Staff members will be responsible for explaining the study to participants using the 'easy read' information sheet and for gaining consent using the 'easy read' consent form. Clauses in both forms clearly state that participants can withdraw from the project at any time without having to give a reason.

4. Assessing the mental capacity of participants

It could be the case that some potential participants do not have the mental capacity to provide consent for the study.

Precautions taken: No one will be included in the study if they do not have the capacity to consent. This judgement will be made by the principal investigator (See 6. inclusion criteria). Potential participants who have the ability to read text normally can be considered to have the capacity to consent. This will be checked through informal conversation at the face to face meeting with the participant and also by the Participant recruitment profile (Appendix B).

As a further check, and as part of the preparatory measures, participants who are able to read and comprehend text at the 'Beginner Level' on the York Assessment of Reading Comprehension (YARC) (Snowling et al 2011) will be considered to have a level of verbal understanding sufficient to make an informed decision about participating in the study. If the investigator finds that a participant, once embarking on the tasks, does not have sufficient levels of language to ensure that he/she understands the process, the participant will be withdrawn from the study.

5. Being assessed

Participants might feel they are being 'assessed' and could also worry about getting things wrong.

Precautions taken: All participants will be given the option of bringing someone along to the session to support them. The reason for the tasks will be explained fully by staff using the information and consent forms. The investigator will explain the reasons for carrying out the tasks again before embarking on them and will allow time for questions and further explanation of the assessments. Specific reassurance will be given about 'getting things wrong' in the following manner:

'It does not matter if you get things wrong, or if you think you get things wrong. This is because we need to know what things are hard to understand. Getting things wrong and getting things right are both good for the study.'

All scoring sheets that will be used during tasks will be marked or recorded in a way that does not indicate to the participant if they have given a 'wrong' answer or made an error.

Every effort will be made to provide an environment of openness and trust by using positive reinforcement throughout the tasks.

6. Fatigue during the procedure

Participants who find reading difficult might tire easily during the tasks and worry about asking to stop.

Precautions taken: Participants will be reassured that they can ask to have a break at any time. If the investigator judges that performance is being affected by fatigue rather than by ability, she will stop the task at an appropriate point (i.e. at the end of one of the three tasks rather than in the middle) and arrange to continue after a break or, if necessary the following day.

7. Expectation of remuneration

Participants might expect immediate financial or other personal benefit from taking part

Precautions taken: The information sheet clearly outlines the purpose of the project. It also specifically states that participants will not get anything for taking part in the project, but will be helping to improve 'easy read' material. Staff and/ or family will have gone through this information with the participant, and the investigator will explain this again before starting the tasks.

Specific issues for the principal researcher:

1. Enhanced Disclosure certificate has been issued for the purpose of this study.

Date: 16.0713 Certificate number: 001411453970

2. Working with adults with challenging behaviour

Any risk to the researcher has been minimalized. Gatekeepers are requested to fill out a participant recruitment profile where they are asked to identify any challenges that a participant might present. If there is any concern about the level of risk to the researcher, this will be discussed fully with staff who are familiar with the participant and safety measures will be put in place according to the individual needs and requirements of the participant. This might be

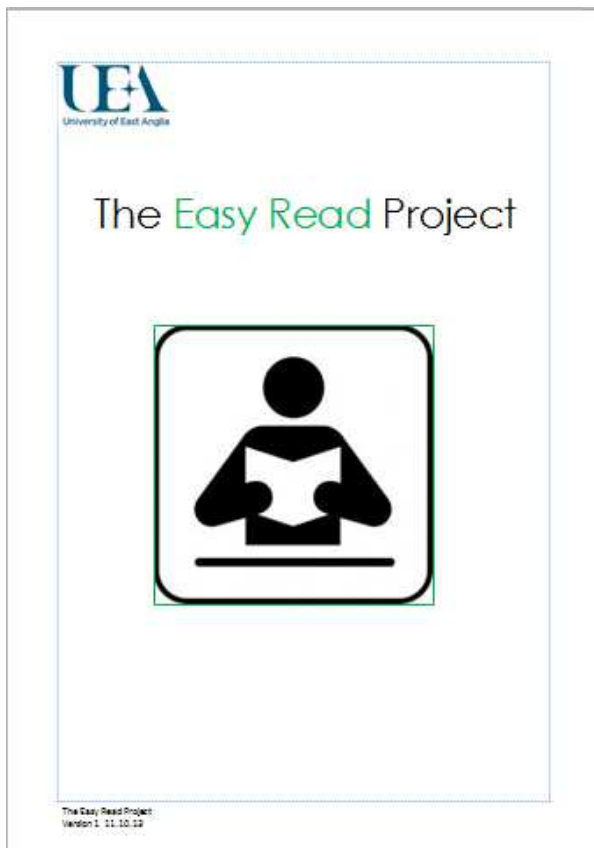
working in a room with the door open or requesting that the participant be accompanied by a familiar member of staff.

3. Completion of UEA Safeguarding Training (working with children and vulnerable adults)


4. HCPC registered: SL14648

5. RCSLT registered: RC0010786

Appendix Chapter 5. iii Publicity Leaflet



Susan Buell is in charge of the **Easy Read** Project.




She works at the University of East Anglia.



She wants to find out what makes **easy read** information easy to understand.








She needs people who use **easy read** information to take part.



Your name:

I would like to take part in the **Easy Read** Project.

		Yes
		No

 I heard about the **Easy Read** Project from:

The Easy Read Project Version 1 11.10.10



If you said yes,



Susan will explain everything about the **Easy Read** Project to you. Then you can decide if you still want to take part.



You can contact **Susan** by email:
s.buell@uea.ac.uk



or by phone:
01603 591009



or give this to:

Appendix Chapter 5. iv Participant Information Sheet 1



The **Easy Read** Project



Information



This information is about the project.




Read the information.




You can decide if you want to take part.




The Easy Read Project Version 3 © 2011



Who is in charge of the **Easy Read project?**

Susan Buell.



Susan works at the University of East Anglia.




This research is for her PhD certificate

What is the project for?

Susan wants to find out what makes **easy read** information easy to understand.


Finding this out will help us to make **easy read** information better.




She needs people who use **easy read** information to take part.



What will happen if you take part?




Susan will ask you to sign a form saying that you agree to take part.




She will ask you some questions about yourself for the project.


What do you have to do?



Susan will ask you to do 3 things.

- Choose the best pictures for some words that she read out.
- Read some writing and give 8 answers to questions about it.
- Read some more writing and give 8 more answers to questions about it.





The Easy Read Project Version 3 © 2011



What will happen to my answers?

Susan will record your answers on an audio recorder,



and on paper.



Who will see my answers?

Karen is Susan's supervisor at UEA.



She might listen to your answers to check her work.



Some other people at UEA might want to see your answers to check Susan's work. This is called an audit.



No one else will see your answers.



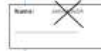
How long will it take?

This will take about 1 hour and 30 minutes to do.



It's private!

Everything you do for the project is kept private and locked up for 5 years.



All your answers are used without your name on them.

You can see them if you want to.



What do I get from the Easy Read Project?

Being part of the project will help us to make **easy read** information better for people with learning disabilities.



You do not get anything from us for being in the project.

The Easy Read Project | Version 3 | 2020



What if you have a question?

If you do not understand something Susan can talk to you about it



You can talk to whoever you want about the project.

You can talk to a friend or someone in your family.



You can stop being part of the **Easy Read** project whenever you want.

You do not have to give a reason to stop.

What will happen afterwards?



Susan will write about what she finds from the project.



This will be part of a bigger project that will be published.

She will write a report for everyone to see.



What if something goes wrong?

You can tell someone you know if you are unhappy with the project.

You can also tell Susan.



You can also contact someone at the Norfolk Community Health and Care NHS Trust Patient Advice and Liaison Service (PALS)

by email: pals@nchc.nhs.uk

or by phone: 0800 0884449.



Thank you for reading this information.

The Easy Read Project | Version 3 | 2020



You can contact **Susan** by email:
s.buell@uea.ac.uk



or by phone:
01603 591009



Susan Buell
School of Rehabilitation Sciences
Queen's Building
University of East Anglia
Norwich Research Park
Norwich NR4 6TJ

Pictures and images used from Change Picture Bank, Google images, Microsoft clipart.

Participant Information Sheet 2



The **Easy Read** Project Information Sheet for carers /key workers

Who is in charge of The Easy Read Project ?

The Easy Read Project is part of a PhD study being done by Susan Buell at the University of East Anglia. It has been approved by the Northampton Research Ethics Committee.

What is the project for ?

The main aim of the project is to investigate what makes easy read information easy to understand for people with learning disabilities, and how we can improve written information to make it more accessible in the future.

What will happen ?

People with learning disabilities who use easy read information are being invited to take part in the project. Participants will have the project fully explained to them by someone who knows them before they decide if they want to take part. They will also have the consent form fully explained before agreeing to take part or signing the form. Participants can withdraw from the project whenever they want to and do not need to give a reason for doing this.

There are 3 activities for each participant to complete:

1. Vocabulary Task

The participant will look at a series of 4 pictures and identify the correct picture for the spoken word that is given.

2. Reading Task

The participant will read (or jointly read) a few sentences in the York Assessment for Reading Comprehension and answer 8 questions about what they have read.

3. The Easy Read Task

The participant will read a few sentences in easy read format and answer 8 questions about what they have read.

The three tasks should not take up more than 1 and a half hours of the participant's

Confidentiality

The consent form and any personal information will be identified by the participant's name. All responses will be noted down in writing and also recorded on a digital audio recorder. Participants' responses will be identified by a code. All personal information, response sheets, and audio recorded information will be confidential and securely stored on UEA premises in locked filing cabinets and on password protected central computer store.

Answer sheets and audio recordings might be seen and listened to by Susan's principal PhD supervisor Dr Karen Bunning, for cross-checking information. Also, if there is an audit at UEA, some of the data might be required for checking. Confidentiality will be maintained at all times.

Data will be stored for 5 years before being destroyed.

There is no payment or other gift for participants who are involved in the project.

Questions

Participants are encouraged to talk to friends, family and others about taking part and to ask for more explanation from Susan if there is something they do not understand.

Results

Findings from The **Easy Read** Project will be written up in accessible format for participants and local organisations in Norfolk. Parts of the project will also be prepared for publication in academic journals and for organisations such as MENCAP.

Complaints

If there are any issues of concern that might lead to an official complaint, these can be made through contacting the Norfolk Community Health and Care NHS Trust Patient Advice and Liaison Service (PALS) by email: pals@ncho.nhs.uk or by phone: 0800 0884449.











Further information and contact details

For further information about the project, please contact:
Susan Buell by email: s.buell@uea.ac.uk or Tel: 01603 591009

Susan Buell
School of Rehabilitation Sciences
Queen's Building
University of East Anglia
Norwich Research Park
Norwich NR4 6TJ

Thank you for your interest in The **Easy Read** Project and for reading this information.

The Easy Read Project Version 2 2021-22

	<p>The Easy Read Project Agreement</p>			
	<p>I have read the information about the Easy Read Project. (dated..... version 1)</p>		<input type="checkbox"/>	<input type="checkbox"/>
	<p>I have had the chance to ask questions about taking part. I am happy with the answers.</p>		<input type="checkbox"/>	<input type="checkbox"/>
	<p>I have thought about the Information.</p>		<input type="checkbox"/>	<input type="checkbox"/>
	<p>I know I can stop being in the Easy Read Project at any time. I do not have to give a reason to stop.</p>		<input type="checkbox"/>	<input type="checkbox"/>
	<p>Other people at UEA can look at my answers to check Susan's work. This is called an audit.</p>		<input type="checkbox"/>	<input type="checkbox"/>
	<p>Susan Buell is in charge of the Easy Read Project.</p>			

The Easy Read Project: Version 1 11.10.13



I agree to take part in the Easy Read Project



Your Name:



Signature:

Date:

For office use only

Consent Form
Participant identification

Name of person taking consent:

Signature:.....

Date:.....

When completed: 1 for partici- pant; 1 (original) for research- er site file

Appendix Chapter 5. vi Participant Recruitment Profile

I

The Easy Read Project



RECRUITMENT FORM: PARTICIPANTS

Individual Details	
Name	
Date of birth (age)	
Gender	
Ethnic background	
First language spoken	
Summary of Communication Skills/Difficulties	
1. How does N communicate? Are there any difficulties?	
2. Tick the box representing the 'best fit' to N's communication skills	1. No usable speech or verbal comprehension <input type="checkbox"/>
	2. All communication is through fragmentary expression; great need for inference, questioning, and guessing by the listener. The range of information, which can be exchanged is limited, and the listener carries the burden of communication. <input type="checkbox"/>
	3. Conversation about familiar subjects is possible with help from the listener. There are frequent failures to convey the idea, but the service user shares the burden of communication with the other person. <input type="checkbox"/>
	4. The service user can discuss almost everyday problems with little or no assistance. However, reduction of verbal expression and/or comprehension make conversation about certain material difficult or impossible. <input type="checkbox"/>
	5. Some obvious difficulties with fluency of expression or facility of comprehension, without significant limitation on ideas expressed or form of expression. <input type="checkbox"/>
	6. Minimal discernable communication difficulties, individual may have subjective difficulties, which are apparent to listener. <input type="checkbox"/>
3. Tick the box representing the	1. No known or observed ability to read or write <input type="checkbox"/>

The Easy Read Project
Version 2 08.01.14

'best fit' to the service user's literacy skills	2. Some social sight reading, uses pictorial support, can write own name & copy write <input type="checkbox"/> 3. Can read large print text, newspaper headlines & write in sentences <input type="checkbox"/> 4. Can read text in books & newspapers; can write letters, e-mails, etc. <input type="checkbox"/>
4. Identify any strategies that help when communicating with this service user	a) Using facial expression <input type="checkbox"/> b) Using signs & gesture <input type="checkbox"/> c) Using objects of reference <input type="checkbox"/> d) Using graphic symbols <input type="checkbox"/> e) Using photographs & pictures <input type="checkbox"/> f) Using short, simple sentences <input type="checkbox"/> g) Using a communication book or board <input type="checkbox"/> h) Using an electronic/computer aided device <input type="checkbox"/> i) Having a supporter (e.g. staff/parent) present <input type="checkbox"/> j) Other – please state: <input type="checkbox"/>
5. Identify any other factors or difficulties that need to be taken into consideration when communicating with this service user	a) Hearing problems <input type="checkbox"/> b) Visual impairment <input type="checkbox"/> c) Physical/motor difficulties <input type="checkbox"/> d) Attention problems <input type="checkbox"/> e) Challenging behaviour <input type="checkbox"/> f) Other – please state: <input type="checkbox"/>
Form completed by	
Name of Informant	
Date	

1

Appendix Chapter 5. vii Definitions of Reading Comprehension Levels

Adapted Levels	Measures (defined by YARC)	Outcomes
Level A	Literal information	Superficial recall of information within the text
	Vocabulary dependent information	
Level B (Inference)	Coherence inference - cohesive devices	Demonstration of linguistic understanding of complex text – for example, able to process information from text to be able to answer a ‘Why?’ question.
	Coherence inference - knowledge based	
Level C	Elaborative inference	Demonstration of expanded recall of information - uses world knowledge and experience of emotional states, cause-effect to help process information in text. What would happen if...? How would it feel if...?
	Evaluative inference	
Level D	Logical /deductive reasoning	Demonstration of deep recall/ processing of information. Requires the ability to use information from text and apply it to a hypothetical situation. Requires application to ‘other’ and perhaps problem solving.

Levels A-D (adapted from Snowling 2011, YARC)

Appendix Chapter 5. viii Reciprocal Reading definitions

Support	Definition	Example
Summary	A brief summary of the main idea within the text. Can be a short sentence reflecting the core message	‘This text is about what to eat and what not to eat if you want to stay healthy.’
Question	A question that the text answers and that reflects the main idea of the text. (Should avoid introducing questions at this point that are directly asked as part of the task)	‘The information here would help you answer a question like...What do you need to eat if you want to stay healthy?’
Clarification	Clarification of the text, in chunks, explaining the information, using gesture, pointing to pictures as appropriate. Specific examples from the text can be used. No further elaboration necessary. Responses to requests for clarification of specific information can be made at this stage.	‘Now we can look at it together and I’m going to explain the information in case there are things that you do not understand.’ ‘Here it talks about protein. That is something in food that helps our bodies. It helps our bodies to grow and also to get better... It says here that you can eat foods with protein like cheese and meat. They will help your body to mend itself or get better.’
Prediction	Provides reader with further elaboration about the text to help with inferential application of information.	‘So for example, if I cut my finger, it might help to get better more quickly if I ate some protein. I could eat some meat or cheese.’

(Adapted from Palinscar & Brown 1984)

Appendix Chapter 5. ix Linguistically Simple Text A, Questions and Scoring guide

TASK TEXT A (Flesch Kincaid Grade Level 4)

263 words

We need food and water to grow and be healthy. You should enjoy your food! You need to eat lots of different foods to be healthy.

Fruit and vegetables are good for you. They help you to get vitamins to stay healthy.

You should try to eat 5 portions of fruit and vegetables a day. A portion can be 1 piece of fruit, like an apple, banana or orange or a serving of vegetables, like peas, carrots or broccoli.

Some foods are good for you because they give you energy. They are called carbohydrates. These are foods like bread, potatoes and pasta.

You should also eat food that will help your body go to the toilet. They are called fibres. These foods are: brown bread, brown rice, fruit and vegetables, and breakfast cereals, like Weetabix and porridge.

Some foods are good for you because they help your body to grow and mend itself. They are called proteins. These are foods like meat and meat pies, chicken, fish, fish fingers, eggs, baked beans, lentils, nuts and peanut butter.

Foods like milk, cheese and yoghurt are good for you because they give you calcium. Calcium helps your bones and teeth to stay strong. You should try to have some milk or yoghurt or a piece of cheese every day.

Sugary foods like jam, sweets and cakes are nice to eat, but too much sugar can give you bad teeth and make you put on weight. Too much salt and fat can be bad for your heart. Try not to eat too many crisps and chips.

Text A Easy Read



The Easy Read Project
Text A



 We need food and water to grow and be healthy.

 You should enjoy your food!


 You need to eat lots of different foods to be healthy.

 Fruit and vegetables are good for you. They help you to get vitamins to stay healthy.




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You should try to eat 5 portions of fruit and vegetables a day.

 A portion can be 1 piece of fruit, like an


- apple,
- banana or
- orange

 or a serving of vegetables, like


- peas,
- carrots or
- broccoli.


 Some foods are good for you because they give you energy. They are called carbohydrates.

The Easy Read Project Version 1 11.10.15


 These are foods like

- bread,
- potatoes and
- pasta.

 You should also eat food that will help your body go to the toilet. They are called fibres.

 These foods are:

- brown bread,
- brown rice,
- fruit and vegetables,
- and breakfast cereals, like Weetabix and porridge.



The Easy Read Project Version 1 11.10.15



Some foods are good for you because they help your body to grow and mend itself.

They are called proteins.

These are foods like

- meat and meat pies,
- chicken,
- fish, fish fingers,
- eggs,
- baked beans, lentils,
- nuts and peanut butter.



The Easy Read Project Version 1 11.10.15



Foods like

- milk,
 - cheese and
 - yoghurt
- are good for you because they give you calcium.



Calcium helps your bones and teeth to stay strong. You should try to have some milk or yoghurt or a piece of cheese every day.



The Easy Read Project Version 1 11.10.15



Sugary foods like

- jam,
- sweets and
- cakes



are nice to eat, but too much sugar can give you bad teeth and make you put on weight.



Too much salt and fat



can be bad for your heart.



Try not to eat too many crisps and chips.

The Easy Read Project Version 1 11.10.15

Task questions and scoring guides Text A

Questions for 'Easy Read' Text A

		Question 'From what you have read....	Answer Guide	Classification (YARC)
Level A	1	What foods give you energy?	Carbohydrates/ Bread/ potatoes /pasta	Literal
	2	What does fibre in your food do?	Helps you to stay healthy/ body to go to the toilet/ feel well/ makes you 'go' more/ roughage/	Vocabulary dependent
Level B	3	What helps you get vitamins?	Fruit and vegetables	Coherence inference: linguistic
	4	What foods are not very good for you?	Sugar/ fat/ salt	Coherence inference: knowledge based
Level C	5	What would happen if you stuck to the 5- fruit and vegetables-a-day rule?	Stay healthy/ feel better/ lose weight/ be happier/ more energy/	Elaborative inference
	6	How would you feel if you ate a lot of sugar?	Fat/ overweight/ bad teeth/ unhappy/ unhealthy/ worried/ upset	Evaluative inference
Level D	7	If you had a friend with a bad heart, what advice about food would you give him?	Eat 5 portions of fruit and veg a day/ less sugar/fat/ salt/ less crisps and chips	Logical/deductive reasoning
	8	Someone you know has broken her arm. What are the best foods for her to eat?	Calcium in yogurt, milk cheese; Proteins/ meat/ meat pies/ chicken/ fish/ fish fingers/ eggs/ baked beans/ lentils/ nuts/ peanut butter	

Question 1 and 2 Level A (targets literal and vocabulary dependent information in text)

LABEL	DEFINITION	ELABORATION	EXAMPLE	
Q1 Example TEXT A	(From what you have read....) What foods give you energy? (Literal)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	bread, potatoes and pasta (one or more of the above) BUT reduce to 2 points if other foods are named (if maxim of quantity is flouted see example).	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	jam, sweets and cakes OR bread, pasta, apples, meat', OR apples and broccoli OR fruit/ vegetables	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; information from picture only	Coca cola – that gives you lots of energy OR 'energy drinks' / red peppers / energy to make you strong/	1
Irrelevant/ext aneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; use of textual information to provide incorrect answer; no obvious inferences possible from text	Harry Potter OR Water OR it makes you strong OR energy – is that protein you need?' OR too much energy – I've got that'	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

EXAMPLES OF SCORING RESPONSES (Accept first answer only)

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q2 Example TEXT A	What does fibre in your food do? (Literal)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Helps your body to go to the toilet; helps you go to the loo, helps keep your body healthy; won't get constipated	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	Bread, pasta/ fruit and veg (or named)/ food that helps you be healthy/ cereal is fibre/	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Fibre – 'fruit and fibre' / I have cereal every day / 5 a day. Something to do with the toilet. /She's got a sore stomach	1
Irrelevant/extraneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	I have ham and eggs for breakfast OR it makes you strong OR fibre – good for bones and teeth OR you shouldn't have too much, it's bad	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

Question 3 and 4 Scoring for responses to Level B (targets understanding of coherence inference: cohesive devices/ knowledge based)

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q3 Example TEXT A	What helps you get vitamins? (Coherence inference: knowledge based)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Fruit (3) / vegetables (3)/ (or named minimum 2)	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	Milk, yogurt, cheese, meat, fish, eggs, 2 or more = (2)	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	pills/ orange juice / juices/ brown bread/ cereal (or named cereal)	1
Irrelevant/ext raneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	I wouldn't eat them/ Like on Star Trek/ Protein/ Chips / chocolate/ sugar/ fat/ calcium/ vitamins make you strong	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q4 Example TEXT A	What foods are not very good for you? (Coherence inference: knowledge based)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Sugar/fat/salt,/ chips /crisps/ jams/sweets/cakes /food that makes you put on weight/ foods that give you heart disease/ medical conditions (1 point for any of the above - max 3 points)	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	food that makes you ill/ food that isn't good for bones and teeth / junk food/ unhealthy food	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Fish and chips/ sausages/ biscuits/ puddings/ dentist/ Dr /relevant foods not named in text eg. Twix (picture only: chocolate/ butter)	1
Irrelevant/ext raneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	I try to eat healthily/ Food that helps you go to the toilet going to the doctor/ exercise and losing weight// slimming clubs/ hospitals/choosing food/menus/ getting ill/Pets/ computer games	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

Question 5 and 6 Scoring for responses to Level C (targets understanding of coherence inference: cohesive devices/ knowledge based)

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q5 Example TEXT A	What would happen if you stuck to the 5 fruit and veg a day rule? (Elaborative inference)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	You'd be healthy/ you'd lose weight/ you'd feel better/ you would have lots of vitamins and be strong/ strong heart/ wouldn't get ill	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	You'd be going to the loo a lot/ you might get bored/ might have to eat a lot of ... (name fruit and veg) /keep the doctor away	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	I would waste away/ wouldn't like it/ it would make me feel sick/ too much fruit and veg isn't good for me/ naming fruits and veg from pictures; no link made/	1
Irrelevant/ext raneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	I think exercise is good for you/ it's a lot of cooking/ it's the same as vitamins and protein/ you need lots of water/ I take heart pills once a day/	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q6 Example TEXT A	How would you feel if you ate a lot of sugar? (Evaluative inference)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Feel not good/ unhappy/ bad/ worried /upset/ angry (2) (about because) health/ dentist/ teeth/ put on weight/ get ill/ unable to do things / hypo/diabetes/buzz/ (2) If both (3)	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	(See above) OR Shouldn't do it/ unhealthy/ should eat more apples, fruit, veg/ it's not good for you	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	I like sugar/ chocolate/ /not be worried/ sugar is good if you eat a little bit/ feel fine/ happy/ nice/ I put sugar in my tea/ cake / chocolate / Tunnocks / you would end up in hospital	1
Irrelevant/ext raneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	It wouldn't make any difference/ sugar is really good for you/ we give sugar water to my parrot/ I had to measure sugar to make pancakes/ apple/ banana/	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

Question 7 and 8 Scoring for responses to Level D (Logical and deductive reasoning)

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q7 Example TEXT A	If you had a friend with a bad heart what advice would you give him about food?			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Eat more healthily/ eat 5 a day/ more fruit and veg/ stop eating so much salt/ sugar/ fat (at least 1 =3) (naming any 2 of chips/crisps/ cake/jam/ sweets =2)	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	(See above)/Eat more meat and fish/ eggs/lentils/ milk/yogurt/cheese. Needs protein and vitamins/	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Stop drinking tea and coffee/ more water/ more exercise/ get out and about more/ cut out all the bad things/ go on a diet	1
Irrelevant/extraneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	Go and see the doctor/ try to be happy/ I have a bad heart/ I know someone who had a heart attack/ digestive biscuits/	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q8 Example TEXT A	Someone you know has broken her arm. What are the best foods for her to eat?			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Calcium for bones and teeth/ milk/yogurt/cheese (3) Proteins help the body grow and mend; meat/chicken/fish/eggs/baked beans/lentils/ nuts (3)/	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	5 a day fruit and veg/ healthy food/ need to have fruit – (other named fruit from text)	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Good foods/ not too much sugar and fat/ cereals/ bread/ exercise/ could put on weight /other named fruit/ veg not specified in text or pictured in document	1
Irrelevant/ext raneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	Good teeth/ I know someone who broke an arm / Art/ painting/ fashion/ going on holiday/ go to the Dr/ keep the cast on/slow down a bit/ don't do so much	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

Appendix Chapter 5. x Linguistically Complex Text B, Questions and Scoring guide


TASK TEXT B (Flesch Kincaid Grade 14)

276 words


Healthy Lives, Healthy People (a government report) said the Government would work with communities to involve everyone in making decisions about health. People were involved in saying what proposals should be funded from the public health budget and part of these looks at ensuring that nutrition and obesity are tackled together. This means helping people to eat the right foods to stay healthy.








A number of organisations that work to make sure that we do not get ill will be part of Public Health England, for example, the Health Protection Agency. Public Health England will work with councils and others, helping people to keep healthy, to make sure our plans are right, and to make sure everyone knows what they are doing. However, it is important for people to be able to enjoy food as well as eat a variety of different foods for a healthy diet including the kind of food and drink that will provide them with the vitamins, minerals, energy and fibre that they need every day to help them to stay healthy. As part of a public health policy, they created the 5-a day fruit and vegetable rule (eg. 5 portions of apple, orange, broccoli, carrots). We should also be eating good carbohydrates, found in wholewheat bread, cereals and brown rice which can provide fibre and roughage, as well as eating from protein food groups (meat, eggs and fish), and dairy produce (milk, yogurt and cheese) which provide calcium for strengthening bones and teeth. The foods to eat in moderation are considered to be those high in fat, salt and sugar; high amounts can cause weight gain, heart disease and other medical conditions.

Text B Easy Read



The **Easy Read** Project
Text B












Healthy Lives, Healthy People
(a government report) said the Government would work with communities to involve everyone in making decisions about health.


People were involved in saying what proposals should be funded from the public health budget and part of these looks at ensuring that nutrition and obesity are tackled together.

This means helping people to eat the right foods to stay healthy.


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A number of organisations that work to make sure that we do not get ill will be part of Public Health England, for example, the Health Protection Agency.



Public Health England will work with councils and others, helping people to keep healthy,




to make sure our plans are right,




and to make sure everyone knows what they are doing.


The Easy Read Project Version 1 11.10.13



However, it is important for people to be able to enjoy food



as well as eat a variety of different foods for a healthy diet including the kind of food and drink



that will provide them with the vitamins, minerals, energy and fibre that they need every day to help them to stay healthy.

The Easy Read Project Version 1 11.10.13

As part of a public health policy, they created the 5-a day fruit and vegetable rule eg. a portion of

- apple,
- orange,
- broccoli,
- carrots.

We should also be eating good **carbohydrates**, found in

- wholewheat bread,
- cereals and
- brown rice

which can provide **fibre** and **roughage**,

The Easy Read Project Version 1 11.10.13

as well as eating from protein food groups

- meat,
- eggs and
- fish,

and dairy produce

- milk,
- yogurt and
- cheese

which provide **calcium** for strengthening bones and teeth.

The Easy Read Project Version 1 11.10.13

The foods to eat in moderation are considered to be those high in

- fat,
- salt and
- sugar;

high amounts can cause weight gain,

heart disease and other

medical conditions.

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Questions for 'Easy Read' Text B

	Question 'From what you have read....'	Answer Guide	Classification (YARC)
Level A	1 What foods give you good carbohydrates?	Wholewheat bread/ cereals/ brown rice	Literal
	2 What does fibre in your food do?	Helps you stay healthy/ helps you get roughage	Vocabulary dependent
Level B	3 What helps you get vitamins?	Having a healthy diet/ fruit and veg/ cereals/ eggs/milk/yogurt	Coherence inference: linguistic
	4 What foods are not very good for you?	Sugar/fat/salt	Coherence inference: knowledge based
Level C	5 What would happen if you stuck to the 5- fruit and vegetables-a-day rule?	Be healthier/ feel better/ lose weight/ have more nutrition/ vitamins/ minerals/	Elaborative inference
	6 How would it feel if you ate a lot of fat and salt?	Fat, overweight/ unwell/ heart problems/ other medical problem (identify)/ thirsty/ worried/ unhealthy/ upset.	Evaluative inference
Level D	7 If you had a friend with a bad heart, what advice about food would you give him?	Eat less sugar/fat/ salt /5 portions of fruit and veg a day/ good carbohydrates /roughage/ protein/ dairy/ minerals/ vitamins/ nutrition	Logical/deductive reasoning
	8 Someone you know has broken her arm. What are the best foods for her to eat?	It is important to enjoy food/ need lots of variety of food/ can choose from lots of different foods/ can eat some fat sugar and salt, but not too much/	

- Any response that consists of pointing at word or picture only are scored 1 if considered relevant/ semantically close to target answer.
- Further credit can be given if participant uses relevant transparent gesture to indicate target answer or close to target answer
- Items in red print indicate where picture in document is not supported by text. Only 1 point is given for answers that relate to pictures with no text where no other points are scored.
- Maxim of quantity is observed in scoring all answers. If too much information is given along with some correct information, points are given only for text related information. Eg. Q8. '*Baked beans, soups or sandwiches or beans on toast for them*'(1), Q4. '*sweets, cake, doughnuts, milkshake, icecream, cheese...butter...ham...that's what I had this morning...a ham toastie...*' (2) OR '*sweets, cake, apples, carrots, fish and things for your bones*' (1)

Questions 1 and 2 Scoring for responses to Level A (targets literal and vocabulary dependent information in text)

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q1 Example TEXT B	(From what you have read....) What foods give you good carbohydrates? (Literal)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	(Wholewheat/ brown) bread, cereals (or named), brown rice (one or more of the above =3) BUT reduce to 2 points if too many other foods are also named (ie. if maxim of quantity is flouted see example).	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	Fruit and OR veg (apple, orange, broccoli, carrots)/ 5-a-day/ milk, yogurt, cheese/	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Drink a lot of water/ Lots of different food/ foods with calcium/ protein/ fat/ sugar/ salt/ good for bones and teeth	1
Irrelevant/ extraneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	Harry Potter /I eat at the HUB/ Sainsbury's/ chocolate / cakes/ butter/ chips	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q2 Example TEXT B	What does fibre in your food do? (Literal)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Provides roughage/ helps you go to the toilet/ helps you go to the loo	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	Keeps your body healthy/ keeps you from being ill/ helps you to feel ok/ makes you thirsty/	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	fruit and veg (OR named)/ cereal (or named)/ wholewheat bread/ brown rice give you fibre Lots of different food/ something to do with the toilet/gives you a sore stomach	1
Irrelevant/ extraneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	Harry Potter/ I eat at the HUB/Sainsbury's/ makes you sick/ I don't like all fruit and fibre/ milk and yogurt are good for you	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

Questions 3 and 4 Scoring for responses to Level B (targets understanding of coherence inference: cohesive devices/ knowledge based)

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q3 Example TEXT B	What helps you get vitamins? (Coherence inference: knowledge based)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	A variety of different foods/ fruit and veg/ 5-a-day/ apples/oranges/broccoli/carrots / cereal/ wholewheat bread, Fish, eggs, meat/ milk, yogurt/cheese (min of 2 named)	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	Foods that keep you healthy/ 1 named item from above list	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Pills /Red peppers/ fruit juices/ foods that don't have lots of fat, sugar, salt in them/	1
Irrelevant/extraneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	Energy drinks/ Roughage/ going to the doctor/ exercise and losing weight// slimming clubs/ hospitals/choosing food/menus/ getting ill/Pets/ computer games/ if you enjoy food	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q4 Example TEXT B	What foods are not very good for you? (Coherence inference: knowledge based)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Sugar/fat/salt,/ food that makes you put on weight/ foods that give you heart disease/ medical conditions (1 point for any of the above - max 3 points)	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	food that makes you ill / junk food/ unhealthy food eg. food that is greasy/	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Sausages/ biscuits/ puddings/other relevant foods not in text / dentist/ Dr / chocolate/ butter /chips/ cakes pictured items alone = (1) credit only when no other score	1
Irrelevant/e xtraneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	I try to eat healthily/ Food that helps you go to the toilet going to the doctor/ exercise and losing weight// slimming clubs/ hospitals/choosing food/menus/ getting ill/Pets/ computer games	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

Questions 5 and 6 Scoring for responses to Level C (targets understanding of elaborative and evaluative inference)

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q5 Example TEXT B	What would happen if you stuck to the 5 fruit and veg a day rule? (Elaborative inference)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	You'd be healthy/ you'd lose weight/ you'd feel better/ you would have lots of vitamins and be strong/ strong heart/ wouldn't get ill	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	You'd be going to the loo a lot/ might have to eat a lot of ... (name fruit and veg) /keep the doctor away	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	I would waste away/ wouldn't like it/ it would make me feel sick/ too much fruit and veg isn't good for me/ naming fruits and veg from pictures apple orange broccoli carrot ; no link made/	1
Irrelevant/e xtraneous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	I think exercise is good for you/ it's a lot of cooking/ it's the same as vitamins and protein/ you need lots of water/ I take heart pills once a day/	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q6 Example TEXT B	How would you feel if you ate a lot of sugar? (Evaluative inference)			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Feel not good/ unhappy/ bad/ worried /upset/ angry (2) (about because) health/ dentist/ teeth/ put on weight/ get ill/ unable to do things / hypo/diabetes/buzz/ (2) If both (3)	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	(See above) OR Shouldn't do it/ unhealthy/ should eat more apples, fruit, veg/ it's not good for you	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	I like sugar/ chocolate/ /not be worried/ sugar is good if you eat a little bit/ feel fine/ happy/ nice/ I put sugar in my tea/ cake / chocolate/ Tunnocks / you would end up in hospital	1
Irrelevant/extra neous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	It wouldn't make any difference/ sugar is really good for you/ we give sugar water to my parrot/ I had to measure sugar to make pancakes/ apple/ banana/	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

Questions 7 and 8 Scoring for responses to Level D (Logical and deductive reasoning)

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q7 Example TEXT B	If you had a friend with a bad heart what advice would you give him about food?			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Eat more healthily/ eat 5 a day/ more fruit and veg/ stop eating so much salt/ sugar/ fat (at least 1 =3)	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	(See above)/Eat more meat and fish/ eggs/lentils/ milk/yogurt/cheese. Needs protein and vitamins.	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	Stop drinking tea and coffee/ more exercise/ more water/ get out and about more/ cut out all the bad things/ go on a diet/ from pictures: stop eating: Chocolate/chips/ cake/ butter	1
Irrelevant/extra neous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	Go and see the doctor/ try to be happy/ I have a bad heart/ I know someone who had a heart attack/ digestive biscuits/ Other foods named	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

LABEL	DEFINITION	ELABORATION	EXAMPLE	Score
Q8 Example TEXT B	Someone you know has broken her arm. What are the best foods for her to eat?			
Correct	Precise semantic relation to content and context of text. Fully correct match to target answer	Information is explicitly present in text or paraphrased from text or has clear close semantic relation to text in order to provide target answer	Calcium for bones and teeth/ eg milk/yogurt/cheese (3) OR variety of food/ can choose from lots of different foods eg. protein, fish/ eggs/ meat /dairy (2 = (3))	3
Close	Close semantic relation to content or context of target answer. Partially correct answer.	Information is present in text but not necessarily best match for answering the question; obvious link to semantic content of answer; clear reference is made from text.	Things that would help her to get better/ should eat good things to get better/5-a day/fruit and veg/ cereals and wholewheat bread	2
Distant	Distant semantic relation to content or context of target answer. Tangentially correct.	Information might not be stated explicitly in text (and is more than repetition of information in question); reasonable link to semantic content of target answer; possible inference can be made from text; OR information from picture only	no fat or sugar// eat plenty of chicken / fruit/ veg not named in text/ other relevant food not named in text eg. fromage frais	1
Irrelevant/extra neous	No semantic relation to content or context of target answer, incorrect answer	Information not present in text; no reasonable link to semantic content relevant to answer; OR use of textual information to provide incorrect answer; inferences possible from text but incorrect answer	Lots of chocolate/ I broke my arm/ friend had broken arm/ exercise/going to the Dr/ hospital/ getting help /Art/ painting/ fashion/ going on holiday/ do some exercise/ feed herself with the other arm	0
No response	No response given	No attempt to give information; no information given	Silence after prompt /request for repetition/ clarification/ don't know/ don't understand /can't do it / No	0

Appendix Chapter 5. xi Record Sheets

TEXT A



The Easy Read Project



RECORD SHEET

Participant number:

Date:

Condition:

Raw Scores:

1	2	3	4	5	6	7	8

Total Score:

Researcher:

Susan Buell, UEA

TEXT A	RANDOM ORDER	Question	Answer/Guide /Target for 3 points	Answer Given	Comment/repetitions	SCORE
Level A Literal		FROM WHAT YOU HAVE READ... 1 What foods give you energy?	bread, potatoes and pasta (one or more of the above = 3) BUT reduce to 2 points if other foods are named (if maximum quantity is flouted).			
Vocabulary dependent		2 What does fibre in your food do?	Helps your body to go to the toilet; helps you go to the loo; helps keep your body healthy; won't get constipated			
Level B Coherence inference: linguistic		3 What helps you get vitamins?	Fruit 3/ vegetables 3/ (or named minimum 2 for 3 points)			
Coherence inference: knowledge based		4 What foods are not very good for you?	Sugar/fat/salt / food that makes you put on weight/ food that give you heart disease/ medical conditions (2 or more of any of the above = 3) chips and crisps/ jams/sweets/ cakes = (2)			
Level C Elaborative inference		5 What would happen if you stuck to the 5- fruit and vegetables-a-day rule?	You'd be healthy/ you'd lose weight/ you'd feel better/ you would have lots of vitamins and be strong/ strong heart/ wouldn't get ill			
Evaluative inference		6 How would you feel if you ate a lot of sugar?	Feel not good/ unhappy/ bad/worried / upset/ angry (2) (about/because) health/ dentist/ teeth/ put on weight/ get ill/ unable to do things / hypo/diabetes/buzz/ (2) if both "feeling" + reason (3)			
Level D Logical/ deductive reasoning		7 If you had a friend with a bad heart, what advice about food would you give him?	Eat more healthily/ eat 5 a day/ more fruit and veg/ stop eating so much salt/ sugar/ fat (at least 1 =3) naming any 2 of chips/crisps/ cake/jam/ sweets =2			
		8 Someone you know has broken her arm. What are the best foods for her to eat?	Calcium for bones and teeth/ milk/yogurt/cheese (3) Proteins help the body grow and mend; meat/chicken/fish/ eggs/baked beans/lentils/ nuts (3)		Total	
			The Esri Read Project Version 2.01.06.14			

FURTHER COMMENTS:

BPVS SCORE:

YARC SCORE AND LEVEL:

TEXT B



The Easy Read Project



RECORD SHEET

Participant number:

Date:

Condition:

Raw Scores:

1	2	3	4	5	6	7	8

Total Score:

Researcher:

Susan Buell, UEA

TEXT B	RANDOM ORDER	Question	Answer Guide / Target for 3 points	Answer Given	Comment/ repetitions	SCORE
Level A Literal	1	FROM WHAT YOU HAVE READ... What foods give you good carbohydrates?	(Whole)wheat/ brown bread, cereals (or named), brown rice (one or more of the above =3) BUT reduce to 2 points if too many other foods are also named (ie. if maxim of quantity is flouted).			
Vocabulary dependent	2	What does fibre in your food do?	Provides roughage/ helps you go to the toilet/ helps you go to the loo			
Level B Coherence inference: linguistic	3	What helps you get vitamins?	A variety of different foods/ fruit and veg/ 5-a-day/ apples/ oranges/ broccoli/ carrots / cereals/ whole bread, fish, eggs, meat/ milk, yogurt/ cheese (min of 2 named)			
Coherence inference: knowledge based	4	What foods are not very good for you?	Sugar/fat/salt/ food that makes you put on weight/ foods that give you heart disease/ medical conditions (1 point each for any of the above - maximum 3)			
Level C Elaborative inference	5	What would happen if you stuck to the 5- fruit and vegetables-a-day rule?	You'd be healthy/ you'd lose weight/ you'd feel better/ you would have lots of vitamins and be strong/ strong heart/ wouldn't get ill			
Evaluative inference	6	How would you feel if you ate a lot of sugar?	Feel not good/ unhappy/ boss/ worried / upset/ angry (2) (about because) healthy/ dentist/ teeth/ put on weight/ get ill/ unable to do things / hypo/ diabetes/ buzz (2) If both (3)			
Level D Logical/ deductive reasoning	7	If you had a friend with a bad heart, what advice about food would you give him?	Eat more healthy/ eat 5 a day/ more fruit and veg/ stop eating so much salt/ sugar/ fat (at least 1 =3)			
	8	Someone you know has broken her arm. What are the best foods for her to eat?	Calcium for bones and teeth/ eg milk/ yogurt/ cheese (3) OR variety of food/ can choose from lots of different foods eg. protein, fish/ eggs/ meat / dairy (2 = (3))		Total	

FURTHER COMMENTS:

BPVS SCORE:

YARC SCORE AND LEVEL:

Appendix Chapter 5. xii Easy Read support sheets

Conditions 1 and 2 With Mediation



The Easy Read Task

The Easy Read Project



You will get some 'easy read' pages to read.



You can have as much time as you need to read the pages.



You can read it out loud or you can read it without speaking.



When you are finished, we can look at it together.
I will explain what the information is about.



Then I will ask you some questions.
There are 8 questions.



Some of the answers are in the Easy Read pages.



It doesn't matter if you think you are wrong or if you don't know the answer.



Being wrong and being right are both good for the Easy Read Project.

Conditions 3 and 4 with No Mediation



The Easy Read Task

The Easy Read Project



You will get some 'easy read' pages to read.



You can have as much time as you need to read the pages.



You can read it out loud or you can read it without speaking.



I can't help you or explain what the information says, so just try and do the best you can.



I will ask you some questions.
There are 8 questions.



Some of the answers are in the Easy Read pages.



It doesn't matter if you think you are wrong or if you don't know the answer.



Being wrong and being right are both good for the Easy Read Project.

Appendix Chapter 5. xiii Mediation Scripts

a) Script (guide) for introducing Task With Mediation

	Script Conditions 1 and 2 Text A/ Text B with Mediation	Action
1	Settle in, thank participant for coming and agreeing to take part, check that participant is comfortable.	pause ; wait for participant to get comfortable
2	Here is a guide for us to follow.	show the 'easy read' support sheet to the participant. (Refer /point to it as the explanation is made).
	This is called The Easy Read Task. I'm going to give you something to read.	show Text A or B pause to reassure /check participant is following information
	Take as long as you want to read it. You can read it out loud or without speaking.	pause and check as above
	It's got pictures on it to help you.	point to pictures
3	When you have finished reading it, we can look at it together. I will explain what it says and give you some help.	pause and check as above
4	Then I am going to ask you some questions. There are 8 questions.	pause and check as above
5	The answers will be about the Easy Read Task.	indicate text
6	You can ask me to say the question again if you want.	pause and check as above
7	It doesn't matter if you don't know the answer. Even if you don't know or if you think you are wrong, it is good information for the project.	pause and check as above
8	I will write down/ record your answers to help me remember them exactly.	Indicate where I will be writing
9	Is that ok? /Shall we start now? /Are you ready?/ Have you got any questions?	Give The Easy Read Text A or B to participant.

b) Script (guide) for introducing Task with No Mediation

	Script Conditions 1 and 2 Text A/ Text B with No Mediation	Action
1	Settle in, thank participant for coming and agreeing to take part, check that participant is comfortable.	pause ; wait for participant to get comfortable
2	Here is a guide for us to follow.	show the 'easy read' support sheet to the participant. (Refer /point to it as the explanation is made).
3	This is called The Easy Read Task. I'm going to give you something to read.	show Text A or B pause to reassure / check participant is following information
4	Take as long as you want to read it. You can read it out loud or without speaking.	pause and check as above
5	It's got pictures on it to help you.	point to pictures
6	I can't really help you or explain what it says, so just try and do the best you can.	pause and check as above
7	Then I am going to ask you some questions. There are 8 questions.	pause and check as above
8	The answers will be about the Easy Read Task.	indicate text
9	You can ask me to say the question again if you want.	pause and check as above
10	It doesn't matter if you don't know the answer. Even if you don't know or if you think you are wrong, it is good information for the project.	pause and check as above
11	I will write down/ record your answers to help me remember them exactly.	Indicate where I will be writing
12	Is that ok? /Shall we start now? /Are you ready? / Have you got any questions?	Give The Easy Read Text A or B to participant.

d) Script (guide) for Literacy Mediation Text A

Mediation Text A	Script
Summary	This is about what to eat and what not to eat if you want to stay healthy.
Clarification of each section in text	<ul style="list-style-type: none"> • Here it tells us that we need food and water for 2 things – to grow and to be healthy. • It talks about fruit and vegetables – and about eating 5-a-day. This helps us get vitamins • Then it gives some examples of things you can eat to get your 5-a-day like apples, bananas, oranges, or peas, carrots and broccoli. • This section talks about energy foods. They call them carbohydrates. It gives some examples like bread and potatoes and pasta. • We also need fibre in our diet. This shows that fibre can help you to go to the toilet. There are some examples here of good food with fibre like brown bread, brown rice, fruit, vegetables, breakfast cereal and porridge. • Then there are foods that help your body to recover or to get well. It says here that these are called proteins. Like meat, chicken, fish, lentils... • And foods like cheese, milk and yogurt are good for getting calcium for your bones. Also it helps your teeth. It's good to eat something with calcium every day. • Finally here, it talks about foods that are not so good for you. These are things with lots of sugar and fat. Too much of these foods can make your teeth bad and make you put on weight. Also for your heart, it's not good to eat too much salt and fat like too many chips or crisps.
Example of a possible question that might be asked	So for example, you could ask someone a question about this information, like 'What kind of food is bad for your teeth?' or 'What makes Weetabix and porridge good for you?'
Prediction/ inference about information given in the text	I suppose if I saw some of my friends eating chips every day, I might worry about them putting on a lot of weight or having heart problems. I might try and help them to stop eating chips every day.

(adapted from Palinscar & Brown (1984))

e) Script (guide) for Literacy Mediation Text B

Mediation Text B	Script
Summary	This is about what the government is trying to do about keeping us healthy. They want to help us understand what to eat and what not to eat if we want to stay healthy.
Clarification of each section in text	<ul style="list-style-type: none"> • Here it tells us that the government asked lots of people in the community about what they thought about how the money should be spent. They want to spend the money on problems like 'obesity' – people that are very overweight, and also on 'nutrition' – eating things that are good for our bodies. They want to work together with the council and an organisation called 'Public Health England' to give us information so that we can stay well and not get ill. • They want us to enjoy our food as well as to eat lots of different foods to help stay healthy. • So it talks about fruit and vegetables – and about eating 5-a-day. This helps us get vitamins, minerals, energy and fibre. • Then it gives some examples of things you can eat to get your 5-a-day like apples, oranges, broccoli and carrots. • Here it talks about good carbohydrates. It gives some examples like wholewheat (brown) bread, cereals and brown rice. It says that these can help give you 'roughage' in your diet – this is the same as 'fibre' and it helps you to go to the toilet. • Then there are foods that help you to stay well because they have protein in them, like meat, eggs and fish. • And foods like cheese, milk and yogurt are good for getting calcium for your bones. Also it helps your teeth. • Finally here, it talks about foods that are not so good for you, that we should eat in small amounts not very often. These are things with lots of sugar and fat and salt. Too much of these foods can make you put on weight. Or you could get heart problems or have other problems with your health.
Example of a possible question that might be asked	So for example, you could ask someone a question about this information, like 'What is the government trying to do to help us stay healthy?' or 'Why is cereal and brown rice good for you?'
Prediction/ inference about information given in the text	I suppose if I saw some of my friends putting a lot of sugar in their tea every day, I might worry about them being unhealthy or having problems with their teeth or with their health. I might try and help them to stop taking so much sugar every day.

(adapted from Palinscar & Brown (1984))