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# **An empirical examination of the use of Easy Read texts in health consultations involving patients with Intellectual Disabilities**

## **Abstract**

### Background

Easy Read health information (ERHI) has the potential to promote engagement in healthcare for people with intellectual disabilities (ID). This study examined how ERHI was actually employed by clinicians and received by patients.

### Method

Video recordings were made of 32 patients with ID attending a health check with primary care clinicians who had been given access to a range of ERHI, and 9 attending a health appointment with a specialist ID nurse. The recordings were analysed using Conversation Analysis.

### Results

ERHI was visible in only 6 (19%) of the primary care health checks (though not always shared with the patients). ERHI was used in sequences where clinicians offered unsolicited health advice and met with degrees of resistance from patients, though its potential for shared decision-making was also evident.

### Conclusions

ERHI can aid patient understanding and decision making, but attention should be paid to the interactional practices accompanying their use.

## **1. Introduction**

'Easy Read' is the term given in the UK to adapted written resources that are created for people with ID (intellectual disabilities) typically using short sentences, jargon-free language and verbal text supported or explicated through visual images. If we consider how these texts are represented in policy, research and practice we can see that they are associated the hope that they will transform social opportunities for people with ID, offering possibilities of empowerment and independence through using these texts (Change, 2015; Department of Health, 2010; NHS England, 2015). There is also an aspiration that Easy Read health information will be part of the solution to the persistent and troubling health inequalities experienced by this group (Emerson & Hatton, 2013) as health information in an Easy Read format has the potential to enhance the health literacy of people with ID and their ability to understand and make use of health information and advice (Krahn, Hammond, & Turner, 2006).

Since the emergence of formal guidance about adapting written information for people with ID in the 1990s (Bashford, Townsley, & Williams, 1995; Freyhoff, Hess, Kerr, Tronbacke, & Veken, 1998; Moffat, 1996), Easy Read information has proliferated across the world under different names including Easy English (Australia), Leichte Sprache (Germany) and Selko Kielen (Finland). It is particularly widespread in the UK (Walmsley, 2010) where it has become something of a stock-in-trade for specialist ID services.

Easy Read clearly has a political and ideological value as a means of signaling the inclusion of people with ID as citizens (Mander, 2015; Norah Fry Research Centre, 2004). However, there is a lack of research that attests to the direct impact of Easy Read information on the knowledge or health behaviours of people with ID, as the majority of research has examined either processes involved with designing Easy Read resources, or the views of a range of stakeholders about using Easy Read materials (Boyden, Esscopri, Ogi, Brennan, & Kalsy-Lillico, 2009; Chinn, 2019; Clark, 2002; Mander, 2015). Two recent reviews of existing research on Easy Read resources designed for people with ID (Chinn & Homeyard, 2016; Sutherland & Isherwood, 2016) concluded that despite the widespread commitment to creating and disseminating Easy Read resources (it is increasingly the case that NHS trusts share patient leaflets online in an Easy Read format), evidence for its effectiveness in terms of demonstrably facilitating understanding, is limited.

Moreover, both reviews flagged up the lack of research available on how Easy Read materials are used in practice and the role of supporters in facilitating reading of an Easy Read text. Chinn and Homeyard (2016) note that little of this research takes account of psychological and social science research into literacy, particularly the framework of the **literacy event**. This term is taken from the theory of literacy as social practice advanced by the researchers associated with the New Literacy Studies (NLS) (Barton & Hamilton, 1998; Gee, 1996; Street, 2003). Their body of work has challenged the idea that literacy constitutes decontextualized individual cognitive skills. Instead, it focuses on the institutions and social relationships through which literacy is constituted, and conversely how literacy practices constitute certain kinds of citizenship and social identities. *Literacy events* can be defined as ‘any occasion in which a piece of writing is integral to the nature of participants’ interactions

and their interpretative processes' (Heath, 1983: 93). Literacy events are often embedded in more extensive social practices; for instance a visit to the GP might involve reading an appointment letter, filling in a pre-visit form, being given patient information leaflets to read, and reading a patient insert in a prescribed medication (Papen, 2012).

There has been some valuable research on everyday literacy practices and events that involve people with ID (Moni & Jobling, 2014; Morgan, Moni, & Cuskelly, 2013), though this is still an under-researched area. The current study addresses a gap in the literature to explore how health consultations involving patients with ID can be viewed as containing literacy events in which different practices involved in interaction with texts are made evident.

The study design and methodology were intended to answer the following research questions:

- a) What are the circumstances within which clinicians introduce Easy Read Health Information (ERHI) materials into the health consultations involving people with ID?
- b) How are the ERHI resources introduced and their use warranted?
- c) How are the ERHI resources received by patient with ID and their supporters?

## **2. Methods**

### Research design

The study was a non-consecutive case series of patients attending health consultations in GP or specialist ID health team settings. Conversation Analysis (CA) was used to examine the

interactional micro-practices that frame literacy events involving Easy Read Health Information (ERHI) texts. CA involves the fine-grained analysis of communication, using an established methodology, to reveal how social goals are enacted through talk in interaction (Ten Have, 2007). Initially grounded in Harvey Sacks' sociological explorations of everyday, informal conversation (Sacks, 1992), CA research has been extended to a range of institutional contexts, including medical consultations (Heritage & Maynard, 2006). Studies have examined how clinicians and patients use institutionally sanctioned communicative strategies to achieve social goals relevant to this setting, such as eliciting the patient's concerns (Robinson, 2006), taking and providing a history, proffering a diagnosis (Perakyla, 1998), making and responding to treatment recommendations (Stivers et al., 2018) etc.

CA differs from other qualitative and quantitative research in health communication, by using data from naturally occurring interactions to examine consultations as they unfold, rather than relying on post-hoc interviews or surveys. Moreover CA does not use a predetermined coding system (Roter & Larson, 2002) to categorize clinician or patient communications, thus prioritizing participants own understandings and responses to talk and allowing for an appreciation of the communicative value of often overlooked aspects of talk such as silences, overlaps and non-verbal behaviours.

The study also draws on insights from CA research on interactions involving people with ID (Antaki, 2012). CA investigations of these interactions has revealed that despite demonstrations of interactional competence, presumptions about communicative deficits made by conversation partners can lead to people with ID being denied the normative

speaking rights and obligations accorded to competent members of the speech community (Antaki, Finlay, & Walton, 2009; Antaki, Walton, & Finlay, 2007).

### Participants and recruitment

The study involved two sets of health staff - general practice (GP) primary care staff and specialist ID nurses working in Community Learning Disability Teams (CLDTs). The GP data was all collected in the context of the English NHS Learning Disability (LD) Health Check. These checks were introduced in 2008 as a 'reasonable adjustment' to primary healthcare services in line with the requirements of UK equalities legislation and in reaction to reports of pronounced health inequalities experienced by people with ID (Heslop, Blair, Fleming, Hoghton, & Russ, 2013). Recruiting GP staff undertaking these checks meant that the presence of the patient with ID was ensured. As people with ID make up only a relatively small minority of the patient population in primary and secondary care, it can be a challenge to recruit sufficient numbers of eligible participants among routine users of primary or secondary healthcare services. The rationale for including CLDT clinicians was that they might use different communicative strategies based on their more extensive experiences with patients with ID compared to the primary care staff, and also that they were more likely to routinely use ERHI.

National Institute for Health Research (NIHR) primary care clinical research networks (CRN) helped with the recruitment of GP practices across London. To be eligible for inclusion, practices needed to have undertaken at least 5 learning disability health checks during the previous 12 month reporting period. Sampling was through self-selection; eligible GP

practices that responded to the NIHR CRN notices or to a phone contact by the researcher were included until the sample target of approximately 30 health checks had been achieved.

A smaller convenience sample of specialist ID nurses working in Community Learning Disability Teams (CLDTs) was recruited through the researcher's professional and research networks. They were asked to select appointments where the focus of the consultation was exchange of health information (rather than risk and eligibility assessments etc.). All CLDT staff with a direct clinical role were welcome to participate, though only qualified nursing staff elected to take part in the study. In all of the study sites, patients were eligible to participate if they were over 18, on the GP learning disability register or CLDT caseload, and did not need support from an interpreter because of lack of familiarity with English. Table 1 lists all participants in the study and their roles.

Table 1 here

Legend: Participants' details

## Ethics

Ethical approval for the study was granted by an NHS Research Ethics Committee.

The initial contact to potential patient participants was made by the GP practice. The researcher then followed up with a phone call to interested patients who had given their permission to share their contact details. For those who wished to proceed, a follow up visit was arranged during which information about the project was shared via a DVD and an Easy Read participant information document, both created with the assistance of people with ID. Where individuals were judged unable to give informed consent to participation, a Personal



or Nominated Consultee (Secretary of State and Welsh Ministers, 2008) guided the researcher on the advisability of involving the individual in the study.

## Procedure

During the recruitment process, all of the GP staff were shown examples of ERHI and given access via a Dropbox link to an electronic library of ERHI that had been selected after consideration of the most common health issues experienced by people with ID (Sutherland, Couch, & Iacono, 2002; van Schrojenstein Lantman-de & Walsh, 2009). This library reflected the expressed preferences of two focus groups conducted with people with ID and their supporters who reviewed a range of ERHI resources over a period of three months. The GP staff reported that they were largely unfamiliar with such resources and did not use them routinely in their work with patients with ID (though some did use Easy Read appointment letters and distributed Easy Read information about the health check itself). Four of the GP participants also asked for printed hard copies of the ERHI library. Initial meetings with the specialist ID staff confirmed that they were familiar with a range of ERHI, so this group was not given access to specific resources. All groups were given to understand that a key focus of the study was how they might use ERHI in their consultations alongside other communicative strategies.

Video recording of the health checks and CLDT appointments took place over a 12 month period between July 2016 and July 2017. To avoid unnecessary distractions the researcher switched the camera on just before the patient entered the room where the health consultation was taking place and then left, so that she was not present during the

recording. The camera was visible in a corner of the room, and participants knew that they could turn it off at any time. The length of the recordings ranged from 12.5 to 65 minutes.

Reflective interviews were conducted after initial data collection with a subset of 9 of the health staff and 9 of the patients (in four of these cases their family carers were also present and contributed to the interviews). During these interviews, participants watched the video and/or examined the written transcript of the health check that the participant had taken part in. This was an opportunity to hear more about the participants' experience of Easy Read resources during the health appointment.

#### Data analysis

All of the health check recordings and the reflective interviews were transcribed verbatim, with additional communicative features in the health check recordings such as silences and non verbal aspects also noted. Episodes where an EHRI resource was visible in the video were transcribed in more detail using the CA conventions summarized in Table 2 (Hepburn & Bolden, 2013) and formed into a 'collection'.

Table 2 here

Legend: Transcription conventions

Table 2 Transcription Conventions

↑	Upward pitch shift
↓	Downward pitch shift
=	No discernable gap between utterances
.	Falling, end-of-sentence intonation at the end of a turn
?	Strongly rising tone
,	Continuing or slightly rising intonation at the end of a turn
<u>a</u>	Raise in volume or emphasis
:	Prolonging of the sound; multiple colons denote a longer continuation.
°°	Quieter speech
[ ]	Sections of overlapping speech.
(0.7)	Pauses in the talk, measured in tenths of a second
(.)	Pause of less than one tenth of a second.
-	'Cut off' or unfinished delivery
.pt	Lip smacking sound
( )	Unclear section
> <	Increased speaking rate
< >	Decreased speaking rate

In these instances, the video record showed that the resource was brought out, opened or examined by the HCP and on some occasions also handed to the patients (see Table 1).

Putting together a collection of target phenomena is an important feature of CA practice as it allows for an overview of the scope of a phenomenon and the elucidation of features that are common across different cases (Ten Have, 2007). In each of the examples within the

collection further analysis identified the range of sequences of interactional behaviours in which the use of the ERHI was embedded. Particular attention was paid to how the EHRI resources were introduced by clinicians and how they were responded to by patients and supporters. Sections of the transcripts of the reflective interviews that referred to specific sections of the recordings were added to the CA transcripts as memos (Birks, Chapman, & Francis, 2008) incorporating participants' accounts for their behaviour during the health appointments, or further contextual information (for instance previous experiences with health services).

### **3. Results**

The full data set comprised video and audio recordings of 32 learning disability health checks conducted by general practice (GP) staff and 9 video and audio recordings of health consultations between people with ID and specialist ID nurses. Four patients attended health checks by themselves, others were accompanied by supporters who were either family members or people in paid support roles.

The specialist ID nurses who conducted these health consultations worked in four different CLDTs. The two school nurses were present at the consultations that took place with sixth form students participating in 'transition health checks' within the school setting. Again, patients were usually accompanied at these meetings, only two attended their appointments on their own. Overall, participating patients presented with a range of communicative capabilities, from functional to relatively limited with no use of verbal

language. In all except five of the recordings, patients were observed to interact verbally with the health staff.

a) Overall use of ERHI

As shown in Table 1, ERHI leaflets on specific conditions, health advice or medical procedures (e.g. healthy eating and exercise, having a blood test) were visible in the video recording and engaged with in some way (for example by handling, opening the resource, looking at it, handing it to the patient and/or supporter) by at least one of the participants in seven of the GP health checks recordings (22% of the total). In three of these recordings the clinicians were observed looking through an ERHI resource that they did not share with the patient. One of these GPs mentioned the resource, but commented she could not print it out because it was too long. This is itself a noticeable finding; even after encouragement and access to ERHI resources, GP staff only rarely introduced ERHI into the interaction. Moreover, the length of a resource might be a barrier to use.

The specialist ID nurses were more likely to use Easy Read formatted resources of all kinds in their recorded interactions. These were part of the interaction with patients with ID in 4 of the 9 recordings of these staff. These texts were more varied than those evident in the GP settings. Only one constituted ERHI, namely a leaflet on smoking created by the nurse involved in the consultation. Other Easy Read resources were a health record/action plan, a quality of life survey form, and a text co-created by the staff and patient with ID that might be described as a 'life plan'.

b) The resource as an aide-memoire for the GP

In the extracts in this category, the clinician was observed to bring out an ERHI resource and orientate to it nonverbally, but did not refer to its content explicitly or share it with the patient. This behavior was seen in Health Check 1 (HC1) where the participants were the GP and a male patient in his early fifties (Extract 1 below). Fifteen minutes after the beginning of the health check, the GP had weighed the patient and measured his height and waist circumference.

Table 3 Initiating lifestyle advice

Extract 1 (HC1)		
212	Doctor:	Um (0.6) now look (.) these things I measured=y-
213		(.) your blood pressure, your height and your
214		weight (0.2) your waist measurement
215		(0.9)
216	Doctor:	They're all very important [to kee- ]
217	Patient:	[I've got] a rare
218		condition as well don know if you looked on my
219		records
220		(.)
221	Doctor:	[Ke- J syndrome ]
222	Patient:	[I got J syndrome]
223	Doctor:	Yes yeah (.) and (.) when people [do have]
224	Patient:	[Puts on] weight
225		on certain places and makes me feel embarrassed
226	Doctor:	Yea:h?
227		(0.2)
228	Doctor:	.Pt Ih- (.) unfortunately with that condition y-
229		you can put on weight with it=
230	Patient:	=Yeah
231	Doctor:	Which is why it's really important to try and
232		look at your <u>diet</u>
233	Patient:	[Yu:h ]
234	Doctor:	[To see] if it helps (.) now .hh ((Dr reaches into
235		filing tray and takes out booklet))
236		[tell me a-
237	Patient:	[That's why I wanted to go to a sort of gym or
238		something ((while patient is talking doctor has
239		placed the booklet on the desk corner between
240		her and the patient, orientated for her reading
241		position)) because (.) these diet things they
242		tell you to go to every <u>diet</u> shop but I ain't
243		<u>got</u> that sort of money to go out and buy things

Examination of Extract 1 shows that the GP brings out the resource in the local context of a conversation about the patient's weight immediately following the GP's official 'noticing' of the patient's excess weight after measuring him. The GP's utterances from 212 to 216 bringing the patient's attention to the body measurements, can be heard as preliminaries to the forthcoming delivery of health advice relevant to being overweight.

Delivery of this sort of 'lifestyle' advice is a delicate matter, as it carries a moral imputation that the patient has failed as a responsible patient and has not taken adequate steps to look after himself and control his weight. Before the GP can start the expected advice giving sequence, the patient interrupts with an external justification for being overweight. His claim is that his weight is due to his genetic syndrome and therefore outside his control, thus absolving himself from blame (lines 222-225).

The GP's response (a drawn out 'yeah' with a rising intonation) indicates a neutral stance to the patient's telling of his troubles. She concedes that the genetic condition can cause weight gain (line 228), but harnesses this to an injunction to '*try to look at your diet*' (line 232), a relaunch of the lifestyle advice-giving with an additional assessment of this injunction as '*really important*'. It is at this point that the GP reaches for the Easy Read booklet on healthy eating that she had in her file tray (perhaps prepared for this very moment?) whilst starting to request more detailed information about the patient's dietary habits, which could be seen as leading to a 'teachable moment' (Cohen, Clark, Lawson, Casucci, & Flocke, 2011) incorporating suggestions for behaviour change (line 235-237).

After the sequence outlined in Extract 1 the GP proceeds ask the patient to describe his diet.

As he does so, the GP turns the page of the resource, stops at one page and folds the resource over so that page is showing. She secures the resource on the page by placing the blood pressure monitor over it. She does not refer to the resource or incorporate it into the ongoing interaction with the patient. Around 16 minutes later when she is getting things ready to take a blood sample from the patient, she moves the resource back out of sight on the other side of her desk.

The immediate context for the GP reaching for the ERHI appears to be the launching of a lifestyle advice-giving sequence and the patient's demonstrated resistance to this advice and to the implication that his behaviours are to blame for his excessive weight. In fact, the patient goes on to further resist an imputation that his conduct regarding his weight is blame-worthy, by defending his identity as a responsible patient by referring to his intention to go to the gym (238) and externalizing the barriers to changing his diet by complaining about the cost of diet foods (242-244) rather than his own lack of knowledge of healthy eating, motivation or 'will power'.

However, though the GP glances at the resource and the patient looks at it too, the GP does not refer to the resource verbally and once she has secured it on her desk by placing the blood pressure monitor over it (which obscures part of the page), she pays it no further attention. We cannot know from watching the recordings why the GP chooses not to animate the resource in any way.

However, the memo drawn from the follow up interview with the GP during a reviewing of the recording of the health check adds some further contextual information:



*Interviewer: So, one thing I think I am curious about: the resource sits there and you don't refer to it actually.*

*GP: As GPs we don't tend to go for sort of dietary advice and exercise... we don't get that involved in talking to patients about that very much and I was thinking I'm not actually will I remember everything that I need to say... And I think the resource was there a lot for my behalf...Because I thought if I can't remember, I just want to look at it.*

The GP acknowledges that the health encounter has reached a potentially difficult point where she feels lifestyle advice is warranted. Her assessment is that GPs in primary care tend to steer away from this topic. The GP describes the frame for bringing out the resource is as an aide memoire as she is about to embark on an advice-giving sequence for which she feels unprepared.

c) The resource as an aid to patient decision-making

In Health Check 4 (HC4) and Health Check 5 (HC5), the clinician is observed to bring out the ERHI resource and to refer to it as something that will support decision-making. She then hands it over to the patient for inspection. These two checks are conducted by the same GP and are both with relatively young patients in their early twenties who are accompanied by their mothers. The structure of interaction with the ERHI is quite similar in each health check; focus here is on HC4 which features a female patient (Jeanette), her mother and the female GP.

Table 4 Blood Test

#### Extract 2 (HC4)

635 Doctor: Would you think of having a blood test?  
636 (0.8)  
637 Patient: .Pt um make it sore and (0.2) .hh it's really  
638 delicate (0.3) so ( ) because (0.3) really  
639 hurts (.) [some]times  
640 Doctor: [H m ]  
641 Doctor: >Okay< (0.6) you might notice a little ↓prick  
642 (.) when you get it done, that's right, .hh:: um  
643 (0.5).pt (0.8) but if you've not had blood  
644 test in a long while I could give you a little  
645 bit of information what it actually involves  
646 going for a blood test (.) and maybe you can  
647 have a think about ↓it (0.2) and and at some  
648 point do ↑have ↓them  
649 Mother: ((Nods head))

#### Extract 3 (HC4)

660 Doctor: I'll give you that information and the ↓form,  
661 you have a think about it if you think (0.3)  
662 nah (0.3) I'm not quite ready (0.4) okay but if  
663 you think (0.5) that might be something you  
664 could go for then that would be really  
665 helpful (0.3) you know to .hh make sure you  
666 get as well as possible

#### Legend: Blood test

This literacy event involving ERHI in both HC4 Extracts 2 and 3 begin with the GP raising the question of the patient having a blood test (line 635). Like the previous example of introducing the topic of diet and exercise, topicalizing blood tests is potentially a tricky issue for GPs in the context of the learning disability health check. First, it is not very clear what the GP or nurse's responsibilities might be regarding steering their patient with learning disabilities towards having a blood test. The most up to date template for conducting the test (NHS England, 2017:7) states that health staff should '*Consider clinically relevant blood tests according to current guidelines*', rather than make them a routine part of the check.

However, blood tests are a more significant issue for patients with particular conditions that need to be monitored in this way (Heslop, Hoghton et al., 2013), and the patient in Health Check 4 is one of these patients; she has Down's Syndrome which puts her at a higher risk of hypothyroidism.

However fear of needles is not uncommon among people with ID, as attested by a number of reports (Edwards & Northway, 2011; Kupzyk & Allen, 2019). Perhaps with this in mind, the GP frames the idea of a blood test as something the patient might only think about at the moment, implying that the patient is the decision-maker, with the decision itself being placed in the future (line 635). The patient resists this invitation to consider a blood test; the pause at line 636 and her carefully worded justification for refusal, emphasizing the discomfort associated with needles in a hearably complete and comprehensive three part list (Jefferson, 1991) in lines 636 to 637 (*'make it sore...really delicate...really hurts'*) indicate her understanding that this is a 'non-preferred', or socially non-conforming, response to an invitation (Schegloff, 2007). Non-preferred responses are often treated as requiring some additional interactional work by respondents to mitigate any social discomfort they occasion (Pomerantz & Heritage, 2012), in this case the patient adds an account for her refusal.

The GP receives this information with an acknowledgement that there is pain involved in a blood test, though downgrades this from the patient's *'really hurts'* to *'a little prick'*. She then introduces the resource in low-key terms as *'a little bit of information'* (line 642- 643) which covers *'what it actually involves going for a blood test'*. She formulates the patient's need as one for accurate information about the test in order to make a decision, though sensitively does not characterize the patient's need for health information as being internal

to the patient or linked to any intrinsic incompetence – the circumstances of the need for information are posited in the context of the patient not having had a blood test in a long while (lines 641-2).

The GP projects how the patient might use an informational resource to make a decision about having a blood test. She clearly favours the outcome that patient will decide to have the test (lines 662-65). Nevertheless she raises the possibility that after being better acquainted with the information, the patient might decide not to go ahead and signals acceptance of this eventuality. She uses what could be described as imaginary, or hypothetical reported speech (Myers, 1999) which models a possible future utterance the patient might make having read the relevant information (*'nah, I'm not quite ready'*) – though this not framed as an outright refusal, but a temporally bounded state of being *'not quite ready'*.

Table 5 Blood test leaflet

Extract 4 (HC4)

690 Doctor: This is for you to take home=you have a look

691 through it

692 Mother: Oo::

693 Doctor: ((Doctor hands leaflet to the patient))

694 Okay and=

695 Patient: =Here you go ((patient hands leaflet to mother))

696 (0.4)

697 Mother: Okay we can have a look though it to[gether,

698 Doctor: [Yep

699 Mother: Jeanette [yeah]?

700 Patient: [NO::]

701 Mother: N:o?

702 Doctor: .Hh yeah? (0.2) don't don't worry. If not (0.6)

703 you come back next year and [we'll see how you are

704 Mother: [Yeah

705 Doctor: and have another look at it.

706 Mother: That's really [good

707 Doctor: [But you can take it home, there's

708 no harm in [taking the paper home is it.

709 Mother: [Yeah

710 Mother: Yeah just looking we're just looking

711 Doctor: Hmm?

712 (2.1)

713 Mother: Yeah that's really ↑good

714 (1.5)

715 Doctor: Cause quite often it's something that can appear

716 scary but once you know (0.3) what's actually

717 realistically being done

718 Mother: Hmm::

719 (1.3)

720 Doctor: .Pt it gets much less scary.

721 ((During this long gap in the talk, the doctor is

722 typing on the computer and the patient and her

723 mother are looking at the leaflet)) (37.46)

724 Mother: °And she just holds a piece of cotton wool there

725 and it's all done°

The GP prints out the ERHI leaflet on blood tests using the colour printer in her consulting room and invites the patient to 'look through it' (Extract 4). The resource is structured around a series of photographs and short sentences that show the steps involved in having a blood test. The patient's mother receives the offer of the informational resource from the GP with interest and enthusiasm (line 692). The patient displays further resistance, declining

to handle the resource and upgrading her response to a very definite 'NO' in line 700. The GP and the patient's mother downgrade the patient's obligations vis-a-vis the resource. Instead of instructing the patient to 'have a look through' the resource, she suggests (using the modal participle 'can', rather than a command) that all the patient need to is take the resource home, adding an assessment that an interlocutor would find it hard to disagree with: *'there's no harm in taking the paper home, is it?'* (lines 707 - 708). The mother includes herself as a potential reader, using the first person plural (*'we're just looking'*: line 709), minimizing her daughter's personal obligation to interact with the resource.

From line 720, while the GP types into the computer, the patient's mother engages in a literacy practice that could be described as 'silent reading'. She looks intently at the resource and turns the pages slowly. However, she subtly opens up the option for this to be a joint reading activity with her daughter by orienting her body posture towards her daughter and holding the page open so that her daughter can easily see it (see Figure 1). The patient does indeed indicate at least partial involvement in this role; she turns her head and gaze, if not her torso towards the open page. This interactional practice, termed 'body torque' (Ruusuvuori, 2001; Schegloff, 1998) creates an engagement framework where the patient's attention is visibly 'grudging' or unstable, a framework that her mother reacts to by making her invitation to her daughter to become a co-reader very low key. She shows, but does not read out the written text and makes only a final commentary on the last picture in a quiet voice (as if to herself) *'and she just holds a piece of cotton wool there and it's all done'* (lines 723-724)

Figure 1 Reading the leaflet (HC4)



d) ERHI reinforces unsolicited medical advice

Table 6 Healthy eating leaflet

Extract 5 (HC6)

206 Nurse: So how is your diet at the moment so food wise (.)  
 how  
 207 are you eating  
 208 (0.4)  
 209 Patient: Very well  
 210 Nurse: Very well?  
 211 (0.2)  
 212 Nurse: Pt .hh so: in ter:ms ((reaching across her desk to  
 pick  
 213 up the leaflet)) of fruit and vegetables: (0.4) is  
 your  
 214 diet full of that?  
 215 Patient: Yeah (0.3) I make sure I have um-  
 216 Nurse: Perfect.  
 217 Patient: Yup  
 218 Nurse: So: <in rega:rds to> food these are the kind of  
 things  
 219 we recommend  
 220 (0.5)  
 221 Nurse: .Pt so we recommend if you eat meat (.) ((pointing to  
 222 the page)) making sure you go for lean meat

223 (0.5)  
 224 Nurse: [S:o  
 225 Patient [That's chicken  
 226 (0.3)  
 227 Nurse: ↑Yeah (.) chicken and if you go for red meat getting  
 228 the lower fat meat  
 229 (0.4)  
 230 Patient: Um (.) that would be um >I eat a lot of lamb because  
 231 I'm anaemic<  
 232 (0.2)  
 233 Nurse: Okay hm perfect  
 234 (0.6)  
 235 Lovely .h so we recommend you have at least five  
 lots  
 236 of fruit and vegetables every day okay .hh so this  
 just  
 237 here gives you a bit of information about what a  
 238 portion is=so it could be a handful of grapes for  
 239 e[xample,.hh  
 240 Patient [Uhuh okay  
 241 (0.2)  
 242 Patient: Is that when you say a portion a handful  
 243 Nurse: °A portion° is approximately a handful  
 244 (0.3)  
 244 Nurse: Yeah >so that's perfect< =so I'll give you all this  
 246 information to take home

Table 7 Contraception

Extract 6 (HC6)

486 Nurse: So are you using any contraception at the moment  
 487 so something to:: stop you getting pregnant  
 488 (0.7)  
 490 Patient: Well we do but w- I don't (0.3) I'm not (0.7) °how  
 491 can I put it° (0.9) at this very moment (.)  
 492 we're not [ge-  
 493 Nurse: [Not  
 494 Patient: No.  
 495 Nurse: Okay no worries .hh so if that's something you do::  
 496 (0.3) [come] (.) to have in the future .h then come  
 497 Patient [H m ]  
 498 Nurse: and have a chat with one of us and we can talk you  
 499 through all the different options of contracep[tion  
 500 Patient: [Yeah  
 I  
 501 know b- I know because I n- used to be on the pill



502 once once upon a time

### Extract 7 (HC6)

551 Nurse: But if (.) that is the kind of thing you're  
552 doing (.) one option even if you're not having  
553 (0.6) sex (0.4) one thing you can use is  
554 condoms:=  
555 Patient: =Yes::  
556 Nurse: OK which is something you:: don't need to take  
557 everyday as a pill ((sliding her chair over to  
558 pick up a leaflet from the side of her desk))  
559 [so I can give you::  
560 Advocate: [You can get them from the doctor  
561 Nurse: .Pt little leaflet here just to take home just  
562 in case okay?  
563 Patient: I know how to put it on  
564 Nurse: Yeah?  
565 Patient: tcht huh  
566 Nurse: perfect ah huh huh huh huh  
567 Patient: I'm forty three  
568 Nurse: Hah huh .hh huh huh huh huh. We just like to::  
569 make[a hundred  
570 Advocate: [Yeah but some people don't Carole some people  
571 don't  
572 Patient: I'm forty three::

### Table 8 Smoking

#### Extract 8 (CLDT9)

300 Nurse: So smoking for a long period of time (0.3) it could cause  
301 this (0.4) teeth ((pointing to the leaflet)) it's there  
302 teeth decay  
303 (0.7)  
304 Nurse: Really really bad  
305 (1.4)  
306 Patient: [Yeah  
307 Nurse: [And this one is the: (1.4) ((pointing to the leaflet))  
308 smoking (0.2) will cause this fatal lung cancer so that's  
309 your lung  
310 (0.8)  
311 Patient: Yeah

In these examples, the ERHI is brought into play by the clinician without prior work establishing whether it relates to a health issue that the patient wishes to address. This is observed in Health Check 6 (HC6) and CLDT health consultation 9 (CLDT9). In CLDT9 the specialist ID nurse structures the consultation around a leaflet that she has made herself about smoking, even though from the outset patient has made it clear that he does not want to consider giving up smoking. In Health Check 6 (HC6) the practice nurse brings the patient's attention to two different ERHI leaflets; one on healthy eating (Extract 5) and the other on contraception (Extracts 6 and 7).

In all of the Extracts 5-8 the nurse does less interactional work to warrant her introduction of the ERHI, compared to the GP offering the patient the blood test leaflet in HC4. In fact, it seems that in both cases the patient responds to the nurse's initial query that brings the topic into play (lines 206-207 and lines 486-487) with utterances that could be viewed as adequately closing the nurse's line of inquiry with a 'no-problem' answer. In response to the nurse's question '*how are you eating*', the patient responds '*very well*' and asserts that she is '*making sure*' she has the recommended fruits and vegetables in her diet (line 215), and when the nurse asks the patient whether she is using contraception, the patient replies in such a way that implies that whatever she is doing with her fiancé, contraception is not needed.

Nevertheless, the nurse brings out two the two ERHI leaflets on healthy eating and on contraception that she seems have ready on her desk. On each occasion, she places them on the corner of the desk between her and the patient. She 'joins forces' with the leaflet, using the institutional 'we' (lines 218 – 219, line 233) in the format 'we recommend' to

emphasize that this is message that is sanctioned by medical expertise, rather than just her personal opinion. The nurse also refers to offering unsolicited health information '*just in case*' (line 562) and having '*to make a hundred [percent sure]*' (lines 568-569) which appear to refer to concerns about professional accountability and risk reduction.

In both examples, the patient is positioned as a decision maker. The nurse's utterance regarding healthy eating corresponds to the action of 'recommending', which though it carries a fairly heavy institutional endorsement, is more 'patient-centred' than a command or pronouncement ('go for lean meat' or 'I'd like you to eat more fruit and vegetables'). In terms of recommending condom use, this is offered as one 'option' (though other 'options' are not suggested); again implying that the choice to take up the nurse's advice belongs to the patient (Stevenson, Barry, Britten, Barber, & Bradley, 2000).

It is interesting to see how the patient responds to the recommendation. She resists the imputation of not knowing or lack of epistemic authority (Heritage & Raymond, 2005) that the nurse's design of her utterances implies. She displays her dietary knowledge that 'chicken counts as lean meat' (line 223) and 'lamb is an iron-rich meat' appropriate to her condition of being anaemic (line 229 – 230). She displays her knowledge and experience of contraception (499- 501 and line 563). She also displays her awareness and resistance to the imputation of epistemic disadvantage conveyed by the nurse's and the leaflets' informing practices, using the formulation '*yeah I know*' to assert her epistemic authority in this area (line 500). In lines 567 and 572 she invokes a membership categorization device (Psathas, 1999) that of age to assert the value of her life experience and resist the implication of incompetence that is bound up with the dynamics of this literacy event.

The patient in CLDT 9 uses different interactional resources to express his disinterest in the resource about smoking cessation that the ID nurse presents during their consultation. The text is presented as information rather than explicit advice, though the way that it is personalized to the patient (*'your lung'* in line 309), makes it clear that this advice is being offered in a tendentious manner, directed at eliciting an agreement from the patient that smoking is likely to damage his health and he intends to stop. Heritage & Sefi, (1992) suggest that advice can be heard to be accepted by its recipient when they respond with a marked acknowledgment, such as 'oh right' that treats the information as news to the participant through use of the 'oh' marker and signals its acceptance. Unmarked acknowledgment using receipt objects such as 'mm hm' or 'yeah' on the other hand do not suggest any commitment to attending to the information as advice that will be adhered to and moreover suggests that the recipient already has knowledge of the information.

The patient's responses to the nurse's delivery of information involve the use of unmarked acknowledgment receipts (line 307 and 321) as a form of passive resistance (Heritage & Sefi, 1992) to the nurse's project. Moreover, he produces these only after silences in the interaction (lines 306 and 311) that themselves signal some sort of interactional trouble associated with the import of the prior utterance for the patient.

#### **4. Discussion**

An initial observation is simply that ERHI was used in primary care settings only infrequently with patients with ID, even when additional effort was made to ensure that staff have some

familiarity with ERHI resources, and their access to these resources had been facilitated. Specialist ID nurses were observed to use EHRI more frequently. There were a number of instances within the health check recordings when patients with ID did raise their own concerns or request further health information (though the format of the health check to a large extent removed the need for the patient or their supporter to present a 'doctorable' problem at the outset [Heritage & Robinson 2006]) but GP staff were not seen to respond to these by offering ERHI. Other research with different populations has explored the range of barriers to the effective use of written health information in health consultations, particularly difficulties in locating the right resource for a specific patient (Hamrosi, Aslani, & Raynor, 2014; McClinchy, Dickinson, Barron, & Thomas, 2011). The challenge for the GP staff, who in many of the health check recordings were meeting the patient for the first time, was to have the right resource on hand for the patient, without prior detailed knowledge of the individual's concerns or communication needs. The specialist ID nurses on the other hand were more likely to have had an ongoing relationship with the patient and the opportunity to identify potentially relevant resources before the recorded consultation.

The first research question concerned the circumstances within which clinicians introduce Easy Read Health Information (ERHI) materials into the health consultations involving people with ID. In this study, clinicians were observed to introduce an ERHI resource at points of potential 'trouble' in the consultation. In the examples considered in this paper, the patient had already stated that the behaviour under scrutiny is not a problem for them, or had voiced objections to the clinician's advice, that they lose weight through healthy eating (HC1), or have a blood test (HC4 & HC5), or stop smoking (CLDT 9). The ERHI was being drawn on here as a resource that might add to the authority of the health staff, and to bring

it to the patients' and supporters' attention that the topics represented in the resources were seen as clinically important by the HCP. In HC6 and CLDT 9 the clinician used the 'institutional we' (Drew & Sorjonen, 2011) when presenting the ERHI text so that they spoke with the voice of collective medical authority.

The second research question asked how the ERHI resources were introduced and what warrants were given for their use. The use of ERHI in the examples above illustrate what Uta Papen has called 'imposed' health texts (Papen, 2010:155). The information was given, but not requested by the patient. In the contraception example (HC6), at a slightly later point in the health check, the patient stated twice '*sex is OFF*', which sounds like she did not judge that the leaflet is needed in her particular circumstances. Papen suggests that when patients feel that health texts are being foisted on them in the course of a health consultation, it could be because the clinician's actions are part of a general policy to deliver health promotion messages that are pursued regardless of the patient's reaction. These sorts of conversations are 'schema-driven' (Roberts, Wass, Jones, Sarangi, & Gillett, 2003) and informed by a medical agenda that proceeds irrespective of the patient's needs or preferences for information. They are an example of a 'medical ritual' (Cicourel, 2005), routinely followed practices that embody the clinician's 'folk knowledge' and institutional identity but may have limited intelligibility for patients.

There is therefore a risk that ERHI becomes part of a this bureaucratic medical 'ritual' that is oriented to the clinician's perceived institutional requirement to ensure the patient follows medically sanctioned recommendations rather than being a response to the patient's own concerns, or expressed desire for information. The proffering of advice by clinicians in the

face of a 'no problem' assessment by the patient is not a usual pattern according to research with populations who do not have ID (Guassora, Nielsen, & Reventlow, 2015; Sorjonen, Raevaara, Haakana, Tammi, & Perakyla, 2006). It has been argued that imputations of competence in decision making are less available to people with ID (Rapley, 2004), and that practitioners struggle with relinquishing responsibility for healthcare choices, even though they might endorse the ideology of self-determination for these patients (Jingree & Finlay, 2008; Rouse & Finlay, 2016).

On the other hand, we also can also see in HC4 an example of a literacy event involving an EHRI resource where it was offered in a way to the patient that avoids imputations of incompetence and was presented as an aid to decision making that fits with the patient's own expressed reluctance to follow the GP's health recommendations by preserving the possibility of the patient not agreeing to medical advice. Moreover, the mother's 'silent reading in the presence of' practice meant that the patient could attend to the text without having to demonstrate any commitment to its contents. The mother's role in this literacy event attests to the importance of literacy mediators (Papen, 2010) who facilitate and support access to written texts for disabled people (Chandler-Olcott & Kluth, 2009; Kucirkova, Messer, Sheehy, & Flewitt, 2013).

The third research question concerned how the ERHI resources were received by patients with ID and their supporters. Not surprisingly, under circumstances where patients themselves had not flagged any problems needing remediation through additional information, we can see them presenting resistance in their response to the ERHI. The young woman in HC4 initially refused to handle the resource on blood tests. The patients in

HC6 and CLDT 9 demonstrate resistance to the unsolicited health information conveyed in the ERHI resources in ways (minimal acknowledgement, demonstration of patient competence and knowledge) that are familiar from other accounts of how health promotion is treated as unwelcome or redundant by patients when it is introduced with minimal warranting by clinicians (Heritage & Sefi, 1992; Salter, Holland, Harvey, & Henwood, 2007).

These findings do not point to a conclusion that use of EHRI in real life consultations is necessarily perceived as 'empowering' for patients with ID. There can be an assumption that making sure that health information is accessible will solve the problem of health literacy for people with ID and lead to their effective engagement with such information (NHS England, 2015). However, concerns about the accessibility of the information can eclipse considerations of the personal relevance and import of the content of ERHI for the individual patient (Oldreive & Waight, 2013) as well as an appreciation of the importance of how far the HCP's manner of offering the ERHI acknowledges the patient's individual information preferences and respects their prior knowledge and autonomy in decision making (Mander, 2016).

We can also see that in some examples, the participant who has the most involvement with the resource was not necessarily the patient with ID him/herself. In HC1 the GP explicitly stated that she brought out the resource for her own benefit as a reminder about how to address an unfamiliar topic that also presents the information in a concise and accessible (to the GP) manner, bypassing the patient himself as a co-reader. Guidance on the design of ERHI does suggest that a wide range of readers and staff working with people with ID should be viewed as potential audiences for these resources (NHS England, 2015). This suggests a



role for ERHI texts as artifacts helpful to clinicians in structuring health communication interactions involving people with ID particularly for clinicians who lack confidence in this area (Ziviani, Lennox, Allison, Lyons, & Mar, 2004).

### Limitations

Recruitment of HCPs was largely opportunistic and participants were self-selected, so may not be representative of the range of HCPs who conduct health consultations with patients with ID, with implications for the generalisability of these findings. Participating HCPs' level of experience with patients with ID was not specifically assessed or controlled for in the analysis. Furthermore for the GP staff, the health check structure, in most cases guided by the Cardiff Health Check checklist (NHS England, 2017), encouraged the HCP to briskly run through a list of questions on predetermined topics, usually requiring only a yes or no response, leaving few opportunities for exploring specific health topics in more detail or involving the patient in decision making around health promotion or intervention options. Consequently only a small sample of instances were recorded where HCPs used ERHI and presented here for analysis.

Moreover, more research is needed to examine how patients with ID might make use of ERHI in their home settings and whether EHRIs form part of their health literacy practices (Samerski, 2019). Ethnographic work on health literacy practices suggests that patients often return repeatedly to health information texts as their circumstances change, recruiting others in their social networks to reflect on the information and drawing out different meanings over time (Papen & Walters, 2008).

## 5. Conclusions

These findings present new knowledge regarding how accessible health texts are used as constituents of literacy events with people with ID, the sorts of communicative practices that are associated with their use and with what consequences. It also illustrates how far the use of ERHI in real-life healthcare settings can be seen to be promoting positions for people with ID that we might see as respectful and democratic, rather than undermining of their capabilities.

The aim of the study was not to find fault with hard-working and committed practitioners. The clinicians who participated in the study were often meeting the patients for the first time without much prior knowledge of their life experiences or communicative preferences. In addition they were having to orient to different competing objectives during the health consultations, including establishing rapport, collecting information on pre-determined health topics, encouraging health behaviours and addressing risks. The dilemma facing such clinicians is how to advocate for health-promoting behaviours whilst facilitating participation and involvement of the patient with ID. What this study suggests is that pursuing the clinicians' agenda towards acceptance of medical advice, and using ERHI to do this, can be counter-productive. Like all of us, patients with ID are likely to meet imputations of limited knowledge and competence with resistance and we can see them skillfully exploiting a range of communicative resources to do this.

For practitioners and policy makers, the existence of a legally mandated 'reasonable adjustment' (*Equality Act, 2010*) such as ERHI is an important first step, but crucially, attention must be paid to the context and practices in and through which it is employed. First, simply making resources available does not ensure that they are used. Secondly, practitioners need to be aware that it is all too easy to revert to disabling practices that undermine choice and control for people with ID (Finlay, Walton, & Antaki, 2008) when ideologies of participation and inclusion of disabled people conflict with other competing institutional ideologies of care and medical expertise.

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