

# Characteristics of people with low health literacy on coronary heart disease GP registers in South London

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 Characteristics of people with low health literacy on coronary heart disease GP registers in South London

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#### **Contributions:**

 GR Led on development of the research idea, contributed to interpretation of result, and led on writing the paper

AM collected research data and contributed to interpretation of results and writing the paper

SH collected research data and contributed to interpretation of results and writing the paper

RP led on statistical analysis of the data and interpretation of the results AM co-developed the UPBEAT cohort study in which the study is sited, contributed to the research idea, contributed to interpretation of results and writing the paper

AS contributed to the project design, analysis of results and writing the paper PW contributed to the research idea, interpretation of the results and writing the paper

 AT led o the development of the UPBEAT cohort study in which the study is sited, contributed to the research idea, contributed to interpretation of results and writing the paper

All authors have approved the final version

# Abstract (300 words)

Objective. To explore characteristics associated with, and prevalence of, low health literacy in patients recruited to investigate the role of depression in patients on General Practice (GP) Coronary Heart Disease (CHD) registers (the Up-Beat UK study).

Design. Cross-sectional cohort. The health literacy measure was the Rapid Estimate of Health Literacy in Medicine (REALM). Univariable analyses identified characteristics associated with low health literacy and compared health service use between health literacy statuses. Those variables where there was a statistically significant/borderline significant difference between health literacy statuses were entered into a multivariable model.

Setting. 16 general practices in south London, UK.

Participants: Inclusion: patients >18 years, registered with a GP and on a GP CHD register. Exclusion: patients temporarily registered.

Primary outcome measure: REALM.

Results. Of the 803 Up-Beat cohort participants, 687 (85.55%) completed the REALM of whom 92 (13.39%) had low health literacy. A further 28 participants were excluded from the multivariable analysis due to missing predictor variable data, leaving a sample of 659. The variables remaining in the final model were age, gender, ethnicity, IMD score, years of education, employment; BMI and alcohol intake, and anxiety scores (Hospital Anxiety and Depression Scale (HADS). Univariable analysis also showed that people with low health literacy may have more, and longer, practice nurse consultations than people with adequate health literacy.

Conclusions. There is a disadvantaged group of people on GP CHD registers with low health literacy. The multivariable model showed that patients with low health literacy have significantly higher anxiety levels than people with adequate health literacy. In addition, the univariable analyses show that such patients have more, and longer, consultations with practice nurses. We will

collect 4-year longitudinal cohort data to explore the impact of health literacy in people on GP CHD registers and the impact of health literacy on health service use.

#### Introduction

 Health literacy, 'the cognitive and social skills that determine the motivation and ability of individuals to (access), understand and use information in ways that promote and maintain good health' (1) is a social determinant of health (2). Whilst associated with other social determinants e.g. ethnicity, income, education, and socio-demographic status (SES), it has an independent association with poorer health (3). There are no data on health literacy levels in England; however the 2011 national skills survey has shown that 15% of the adult population (=5 million people) are 'functionally illiterate' (4) (i.e. have insufficient literacy skills to achieve their potential in life and society (5)). It is reasonable to assume that a similar proportion also have low health literacy.

Low health literacy has greatest impact in complex health conditions when patients have to understand procedures, manage medication, and attend multiple appointments. US studies have shown that adults with low health literacy have a higher prevalence of diabetes and heart failure, worse physical and mental health, and higher all-cause mortality (6). There is little research on low health literacy and coronary heart disease (CHD), prompting us to explore this within a longitudinal cohort of patients recruited to investigate the role of depression in patients on General Practice (GP) CHD registers (7). This short report presents initial findings on the prevalence and characteristics of people with CHD and low health literacy.

#### Method

The design, recruitment, power calculation, and measures used in the Up-Beat cohort study were granted ethical approval by the Bexley and Greenwich Research Ethics Committee (REC Reference: 07/H0809/38) (7). Health literacy was measured using the Rapid Estimate of Health Literacy in Medicine (REALM) (8), a 66-item health word pronunciation test highly

correlated with other measures of health literacy (9, 10) and widely used in research studies (3). People with a score of < 58 out of the possible 66 are considered to have low health literacy.

<u>Study design.</u> A cross-sectional analysis of baseline data from the Up-Beat UK Cohort Study (7).

# Statistical Analysis

In order to identify the factors to be entered into the multivariable regression model, the characteristics of those with low health literacy were compared to those with adequate health literacy using  $\chi^2$  tests (categorical variables) and t-tests (continuous variables). Those characteristics where there was a statistically significant (p < 0.05) or borderline significant difference between people with low and adequate health literacy were entered into a multivariable model; logistic regression was used to model predictors of low health literacy. The fit for the model was assessed by the C statistic (ROC curve) and the Hosmer-Lemeshow goodness of fit  $\chi^2$  test.

Analyses were performed using Stata version 11.2.

#### Results

Cohort characteristics are detailed elsewhere (7). Cohort recruitment and a study flow diagram are shown in figure 1.

Figure about here.

The results of the univariable and multivariable analyses are shown in table 1.

**Table: Characteristics by Health Literacy** 

		Health L	iteracy			
		Adequate	Low			
		_		Univariable	Multivariable	
		N (%)	N (%)	analysis	analysis	
Total		595 (86.61)	92 (13.39)	N=687	N=659	
	0,			P-value <sup>(1)</sup>	Adjusted odds of having low health literacy (p-values	
	Soc	io-demographic	characteristics			
Gender	Male	409 (68.74)	75 (81.52)	0.012	0.00 ( 10.004)	
	Female	186 (31.26)	17 (18.48)		0.36 (<0.001)	
	White	536 (90.08)	69 (75.00)	.0.004		
Ethnicity	Other	59 (9.92)	23 (25.00)	<0.001	3.33 (<0.001)	
Age, Mean (SD)	Years	71.13 (10.40)	68.62 (12.09)	0.061 (2)	1.00 (0.933)	
Index of Multiple	10010	11.16 (10.16)	00:02 (12:00)	0.00.	(0.000)	
Deprivation score, Mean (SD)	Range 0-100	18.37 (13.75)	25.10 (13.59)	<0.001	1.02 (0.056)	
Time in	Years	11.99 (3.37)	10.90 (2.57)	<0.001 (2)		
education, Mean (SD)	1 00.10	11.00 (0.01)	10.00 (2.01)	0.001	0.83 (<0.001)	
Employment status	Unemployed/stude nt	14 (2.36)	10 (10.99)	<0.001		
	Paid employment	120 (20.24)	15 (16.48)		0.24 0.063	
	Retired/				0.28	
	Housewife	459 (77.40)	66 (72.53)			
		Lifestyle Chara	cteristics			
Alcohol intake	Doesn't drink	139 (23.40)	41 (45.05)	<0.001	<0.001	
(Units)	1-10 units	297 (50.00)	36 (39.56)		0.43	
	11-20 units	89 (14.98)	7 (7.69)		0.29	
	Greater than	,	,		0.23	
	21units	69 (11.62)	7 (7.69)			
ВМІ	Underweight/ Normal	147 (25.34)	13 (14.29)	0.035	0.033	
	Overweight	257 (44.31)	41 (45.05)		2.31	
	Obese	176 (30.34)	37 (40.66)		2.45	
		Mental He				
Depression score, N	Mean (SD)	2.93 (3.21)	4.07 (3.55)	0.002		
Anxiety score, Mean (SD)		4.47 (4.23)	6.16 (4.96)	0.002 (2)	1.06 (0.035)	
randety coord, mod	` '	sation in the 6 m			(0.000)	
Number of practice			p.101 to b			
(SD)		0.92 (1.89)	1.21 (2.01)	0.044 (3)		
Duration of practice nurse visit, Mean (SD)		5.06 (7.08)	6.79 (8.41)	0.034 (3)		
All other service use variables (4)			(5)	0.191 <sup>(5)</sup> - 0.990 <sup>(6)</sup>		
<sup>1</sup> P-value from t-test	t for continuous variab	les and chi-square	ed tests for cated			
<sup>2</sup> Unequal variances						
Wilcoxon rank sun						

 <sup>4</sup> Number of Accident and Emergency visits, Day hospital and in-patient admissions (days), outpatient visits, GP visits (number, duration), district nurse visits (number, duration), other medical visits (number, duration), other care based visits (number, duration), informal care visits number).

Of the 803 cohort participants 687 (85.55%) completed the REALM questionnaire. The 116 non-responders were excluded from the analyses. Non-responders lived in more socio-economically deprived areas and had received fewer years of education than those who completed the REALM. There was no difference in ethnicity (responders vs non-responders).

Of the 687 participants who completed the REALM, 92 (13.39%) had low health literacy. For the multivariable analysis a further 28 patients were excluded due to missing predictor variable data, leaving a total sample of 659.

The variables remaining in the final model were age, gender, ethnicity (white versus other), IMD score, years of education, employment; BMI and alcohol intake, and anxiety scores (Hospital Anxiety and Depression Scale (HADS)) (11). There was a 6% increase in the odds of low health literacy for every single unit increase in the anxiety score on HADS (range 0-21).

The association between health literacy and IMD scores and employment were borderline significant. There was no significant difference in age.

Service use analysis (univariable only) showed that people with low health literacy had significantly more, and longer, GP practice nurse consultations than people with adequate health literacy, but other service use showed no differences between groups.

#### Discussion

#### Key findings

This study confirms that the characteristics of patients with low health literacy on UK GP CHD registers are similar to those seen in other long-term conditions in studies undertaken in other industrialised countries (i.e.,

<sup>&</sup>lt;sup>5</sup> Number of Accident and Emergency visits

<sup>&</sup>lt;sup>6</sup> Number (days) in-patient visits

membership of a minority ethnic group, socio-economic deprivation, fewer years in education, and lower income (6)). The prevalence of low health literacy is close to that predicted from national general literacy levels (4).

In addition people on GP CHD registers who have higher anxiety levels are more likely to have low health literacy than people with lower anxiety levels. This persists in the multivariable model, indicating an association over and above that already known to exist between anxiety and low socio-economic status (12, 13). This may reflect the findings of Ussher et al that CHD patients with low health literacy have increased difficulty understanding information, less knowledge of heart problems, and increased discomfort about asking for explanations (14). The finding in the univariable analysis that patients with low health literacy had more contact with practice nurses but not with other health services requires further investigation.

# Study limitations

As a cross-sectional study this project cannot demonstrate causality or the impact of low health literacy over time.

Our findings may underestimate of the true picture; the 14.45% of participants who declined to do the REALM share the characteristics of people with low health literacy and may have declined because of reading difficulties.

Our findings of more frequent, and longer, GP practice nurse consultations should be interpreted with caution, as this was found during univariable analysis with no other factors controlled for; no service use data were entered into the multivariable model. The above preliminary finding thus requires more detailed health economic analysis and interpretation.

Finally, the REALM, although highly correlated with tests of functional health and general literacy, is not itself a test of functional skills but of pronunciation.

# Summary

Our findings indicate that there is a disadvantaged group of people on GP CHD registers who have low health literacy in addition to other socio-demographic barriers to health. A new finding is that these people have significantly higher anxiety levels than people with adequate health literacy.

# Next steps

Our possible finding that people on GP CHD registers with lower health literacy consulted practice nurses more frequently will inform future Up-Beat pilot interventions (7) and our longitudinal cohort data will enable us to explore the impact of low health literacy on patients on GP CHD registers, and on their health service use.

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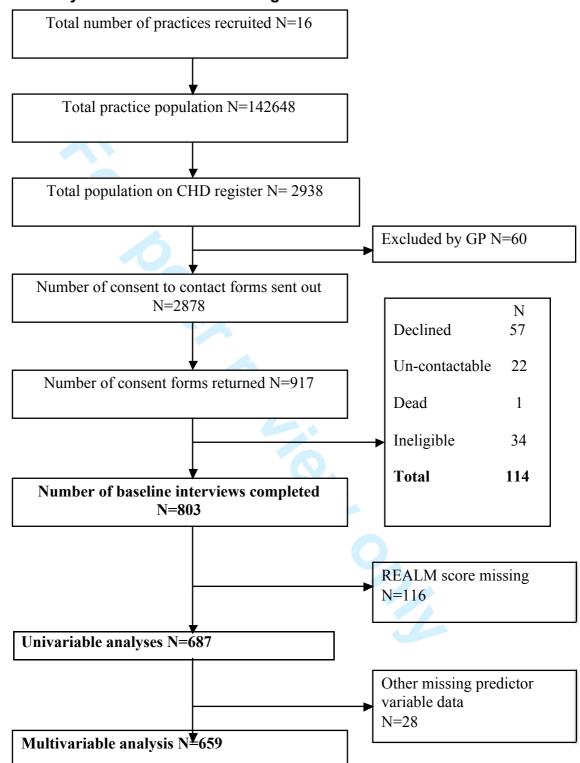
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# **Exploring indicators of low health literacy in a cohort with symptomatic Coronary Heart Disease**

# Figure: Study recruitment: Consort diagram





# Characteristics of people with low health literacy on coronary heart disease GP registers in South London

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#### Contributions:

GR Led on development of the research idea, contributed to interpretation of result, and led on writing the paper

AM collected research data and contributed to interpretation of results and writing the paper

SH collected research data and contributed to interpretation of results and writing the paper

RP led on statistical analysis of the data and interpretation of the results PW conducted additional statistical analysis and contributed to the paper AM co-developed the UPBEAT cohort study in which the study is sited, contributed to the research idea, contributed to interpretation of results and writing the paper

AS contributed to the project design, analysis of results and writing the paper PW contributed to the research idea, interpretation of the results and writing the paper

AT led on the development of the UPBEAT cohort study in which the study is sited, contributed to the research idea, contributed to interpretation of results and writing the paper.

All authors have approved the final version

# Abstract (299 words)

Objective. To explore characteristics associated with, and prevalence of, low health literacy in patients recruited to investigate the role of depression in patients on General Practice (GP) Coronary Heart Disease (CHD) registers (the Up-Beat UK study).

Design. Cross-sectional cohort. The health literacy measure was the Rapid Estimate of Health Literacy in Medicine (REALM). Univariable analyses identified characteristics associated with low health literacy and compared health service use between health literacy statuses. Those variables where there was a statistically significant/borderline significant difference between health literacy statuses were entered into a multivariable model.

Setting. 16 general practices in south London, UK.

Participants: Inclusion: patients >18 years, registered with a GP and on a GP CHD register. Exclusion: patients temporarily registered.

Primary outcome measure: REALM.

Results. Of the 803 Up-Beat cohort participants, 687 (85.55%) completed the REALM of whom 106 (15.43%) had low health literacy. Twenty-eight participants could not be included in the multivariable analysis due to missing predictor variable data, leaving a sample of 659. The variables remaining in the final model were age, gender, ethnicity, IMD score, years of education, employment; BMI and alcohol intake, and anxiety scores (Hospital Anxiety and Depression Scale (HADS). Univariable analysis also showed that people with low health literacy may have more, and longer, practice nurse consultations than people with adequate health literacy.

Conclusions. There is a disadvantaged group of people on GP CHD registers with low health literacy. The multivariable model showed that patients with low health literacy have significantly higher anxiety levels than people with adequate health literacy. In addition, the univariable analyses show that such patients have more, and longer, consultations with practice nurses. We will collect 4-year longitudinal cohort data to explore the impact of health literacy in people on GP CHD registers and the impact of health literacy on health service use.

# **Article summary**

#### **Article focus**

  Identifying the prevalence and characteristics of people with CHD and low health literacy on coronary heart disease GP registers in South London, UK

# **Key Messages**

- The characteristics of patients with low health literacy on UK GP CHD registers are similar to those seen in other long-term conditions in studies undertaken in other industrialised countries
- The prevalence of low health literacy to be close to that predicted from national general literacy levels at 15%
- People on GP CHD registers who have higher anxiety levels are more likely to have low health literacy than people with lower anxiety levels

# **Strengths**

- The data were collected within a prospective cohort study
- There were a wide range of sociodemographic data collected enabling characteristics of patients with low health literacy to be described
- The simultaneous collection of psychological and service use data enabled these to be compared between patients with low and adequate health literacy

# Limitations

- As a cross-sectional study this project cannot demonstrate causality or the impact of low health literacy over time.
- The findings may underestimate of the true picture; the participants who declined to do the REALM may have declined because of reading difficulties.
- Our findings of more frequent, and longer, GP practice nurse consultations should be interpreted with caution; the above preliminary finding requires more detailed health economic analysis and interpretation
- The REALM, although highly correlated with tests of functional health and general literacy, is not itself a test of functional skills but of pronunciation

#### Introduction

Health literacy, 'the cognitive and social skills that determine the motivation and ability of individuals to (access), understand and use information in ways that promote and maintain good health' (1) is a social determinant of health (2). Whilst associated with other social determinants e.g. ethnicity, income, education, and socio-demographic status (SES), it has an independent association with poor health (3). International comparisons of health literacy levels are hampered by differing national definitions; however it is clear that health literacy is an important issue in many industrialised nations. The proportion of the population thought to be disadvantaged through low health literacy ranges from 19% in the US (4) to 55% in Canada (5). A recent survey of health literacy in Europe, where a common definition of health literacy was adopted, shows a range of health literacy skills between nations, with the proportion of the population having suboptimal health literacy skills ranging from 27.3% in the Netherlands to 61.4% in Bulgaria (6). There are no data on health literacy levels in England; however the 2011 national skills survey has shown that 15% of the adult population (=5 million people) are 'functionally illiterate' (7) (i.e. have insufficient literacy skills to achieve their potential in life and society (8)). It is reasonable to assume that a similar proportion also have low health literacy.

Low health literacy has greatest impact in complex health conditions when patients have to understand procedures, manage medication, and attend multiple appointments. US studies have shown that adults with low health literacy have a higher prevalence of diabetes and heart failure, worse physical and mental health, and higher all-cause mortality (9). There is little research on low health literacy and coronary heart disease (CHD), prompting us to explore this within a longitudinal cohort of patients recruited to investigate the role of depression in patients on General Practice (GP) CHD registers (10). This short report presents initial findings on the prevalence and characteristics of people with CHD and low health literacy.

#### Method

The design, recruitment, power calculation, and measures used in the Up-

Beat cohort study are described elsewhere (10). The study was granted ethical approval by the Bexley and Greenwich Research Ethics Committee (REC Reference: 07/H0809/38) (10). Health literacy was measured using the Rapid Estimate of Health Literacy in Medicine (REALM) (11), a 66-item health word pronunciation test highly correlated with other measures of health literacy (12, 13) and widely used in research studies (3). The version of the REALM validated for use in the UK was used. This groups people into 'low' and 'adequate' health literacy with people with a score of < 59 out of the possible 66 being considered to have low health literacy (14).

<u>Study design.</u> A cross-sectional analysis of baseline data from the Up-Beat UK Cohort Study (10).

# Statistical Analysis

 Initial exploratory univariable analysis was undertaken to identify factors independently associated with low health literacy using  $\chi^2$  tests (categorical variables) and t-tests (continuous variables). Multivariable regression analysis was then undertaken to identify those factors that remained significant when all those identified in the univariable analysis were considered together. Those characteristics where there was a statistically significant (p < 0.05) or borderline significant difference between people with low and adequate health literacy were entered into the multivariable model; logistic regression was used to model predictors of low health literacy. The fit for the model was assessed by the C statistic (ROC curve) and the Hosmer-Lemeshow goodness of fit  $\chi^2$  test.

Analyses were performed using Stata version 11.2.

#### Results

Cohort characteristics are detailed elsewhere (10). Cohort recruitment and a study flow diagram are shown in figure 1.

Figure about here.

The results of the univariable and multivariable analyses are shown in table 1.

# **Table: Characteristics by Health Literacy**

N (%)   N (%)   analysis   analysis   N=687			
N (%)		T	
N (%)   N (%)   analysis   analysis   N=687			
Total			
Socio-demographic characteristics   Socio-demographic characteristics		analysis	
Socio-demographic characteristics   Socio-demographic characteristics	otal	N=659	
Male		Adjusted odds of having low heal literacy (p-value	
Female			
Ethnicity	ender	0.32 (<0.001)	
Ethnicity Other 57 (9.81) 25 (23.58) 3.12 (<0 Age, Mean (SD) Years 71.14 (10.41) 68.92 (11.84) 0.049 1.00 (0 Index of Multiple Deprivation score, Mean (SD) Range 0-100 18.34 (13.84) 24.37 (13.24) (0.001 1.02 (0 Index of Multiple Deprivation score, Mean (SD) Range 0-100 18.34 (13.84) 24.37 (13.24) (0.001 1.02 (0 Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 18.34 (13.84) 24.37 (13.24) (0.001 (2) Index of Multiple Deprivation score, Mean (SD) 25.0 (13.44) (10.41) (10		0.32 (<0.001)	
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Age, Mean (SD)         Years         71.14 (10.41)         68.92 (11.84)         0.049         1.00 (0)           Index of Multiple Deprivation score, Mean (SD)         Range 0-100         18.34 (13.84)         24.37 (13.24)         -0.001         1.02 (0)           Time in education, Mean (SD)         Years         12.01 (3.40)         10.92 (2.46)         <0.001 (2)	hnicity	3.12 (<0.001)	
Index of Multiple Deprivation score, Mean (SD)		1.00 (0.873)	
Deprivation score, Mean (SD)			
Time in education, Mean (SD)  Employment status  Unemployed/stude nt Paid employment   117 (20.21)   18 (17.14)   0.31   0.34	eprivation score,	1.02 (0.072)	
Color			
Unemployed/stude	ducation, Mean	0.84 (0.001)	
Status			
Paid employment   117 (20.21)   18 (17.14)     0.31			
Retired/ Housewife		0.31 0.138	
Lifestyle Characteristics			
Alcohol intake (Units)   Doesn't drink	I		
(Units)         1-10 units         289 (49.83)         44 (41.90)         0.48           11-20 units         87 (15.00)         9 (8.57)         0.34           Greater than 21units         68 (11.72)         8 (7.62)           BMI         Underweight/ Normal         145 (25.62)         15 (14.29)         0.024           Normal         250 (44.17)         48 (45.71)         2.38           Obese         171 (30.21)         42 (40.00)         2.50           Mental Health           Depression score, Mean (SD)         2.86 (3.14)         4.28 (3.76)         <0.001 (2)	cohol intake	0.00	
11-20 units	nits)	0.48	
Greater than 21units   68 (11.72)   8 (7.62)     0.24	ŕ		
21units   68 (11.72)   8 (7.62)			
BMI         Underweight/ Normal         145 (25.62)         15 (14.29)         0.024           Overweight         250 (44.17)         48 (45.71)         2.38           Obese         171 (30.21)         42 (40.00)         2.50           Mental Health           Depression score, Mean (SD)         2.86 (3.14)         4.28 (3.76)         <0.001 (2)		0.21	
Overweight         250 (44.17)         48 (45.71)         2.38           Obese         171 (30.21)         42 (40. 00)         2.50           Mental Health           Depression score, Mean (SD)         2.86 (3.14)         4.28 (3.76)         <0.001 (2)	ВМІ	0.02	
Obese         171 (30.21)         42 (40. 00)         2.50           Mental Health           Depression score, Mean (SD)         2.86 (3.14)         4.28 (3.76)         <0.001 (2)		2.38	
Mental Health           Depression score, Mean (SD)         2.86 (3.14)         4.28 (3.76)         <0.001 (2)			
Depression score, Mean (SD) 2.86 (3.14) 4.28 (3.76) <0.001 (2)		2.00	
	enression score M		
	Anxiety score, Mean (SD)		
Anxiety score, Mean (SD) 4.39 (4.13) 6.35 (5.18) <0.001 (2) 1.08 (0) Health utilisation in the 6 months prior to baseline	inicity score, ividal	1.08 (0.002)	
	umbor of proctice		
(SD) 0.89 (1.85) 1.33 (2.21) 0.008	Number of practice nurse visits, Mean (SD)		
(SD) 4.98 (7.05) 6.98 (8.30) 0.008	Duration of practice nurse visit, Mean (SD)		
All other service use variables (4)  0.120 <sup>(5)</sup> - 0.793 <sup>(6)</sup>	All other service use variables (4)		
<sup>1</sup> P-value from t-test for continuous variables and chi-squared tests for categorical variables	-value from t-test	es	

<sup>&</sup>lt;sup>2</sup> Unequal variances t-test used

<sup>&</sup>lt;sup>3</sup> Wilcoxon rank sum test

<sup>&</sup>lt;sup>4</sup> Number of Accident and Emergency visits, Day hospital and in-patient admissions (days), outpatient visits, GP visits (number, duration), district nurse visits (number, duration), other medical visits (number, duration), other care based visits (number, duration), informal care visits number).

<sup>&</sup>lt;sup>5</sup> Number of Accident and Emergency visits

<sup>&</sup>lt;sup>6</sup> Other care based visits (duration)

Of the 803 cohort participants 687 (85.55%) completed the REALM questionnaire. The 116 non-responders were excluded from the analyses. Non-responders lived in more socio-economically deprived areas and had received fewer years of education than those who completed the REALM. There was no difference in ethnicity (responders vs. non-responders).

Of the 687 participants who completed the REALM, 106 (15.43%) had low health literacy. For the multivariable analysis 28 patients could not be included due to missing predictor variable data, leaving a total sample of 659.

Exploratory univariable analyses showed that people with low health literacy were more likely to be male, from a non-white ethnic group, live in a more deprived area, have spent fewer years in education, and were less likely to be employed. Age was borderline significant with people with low health literacy being slightly younger than people with adequate health literacy (difference in mean age between groups 2.22 years).

The variables remaining in the final multivariable model were age, gender, ethnicity (white versus other), IMD score, years of education, employment; BMI and alcohol intake, and anxiety scores (Hospital Anxiety and Depression Scale (HADS)) (15). There was an 8% increase in the odds of low health literacy for every single unit increase in the anxiety score on HADS (range 0-21).

Service use analysis (univariable only) showed that people with low health literacy had significantly more, and longer, GP practice nurse consultations than people with adequate health literacy, but other service use showed no differences between groups.

# **Discussion**

 Key findings

This study confirms that the characteristics of patients with low health literacy on UK GP CHD registers are similar to those seen in other long-term

conditions in studies undertaken in other industrialised countries (i.e., membership of a minority ethnic group, socio-economic deprivation, fewer years in education, and lower income (9)). In contrast to other studies (3-6), the patients with low health literacy in our study were slightly younger than the patients with adequate health literacy, although the difference between groups was small and should be interpreted with caution. We found the prevalence of low health literacy to be close to that predicted from national general literacy levels (7).

In addition people on GP CHD registers who have higher anxiety levels are more likely to have low health literacy than people with lower anxiety levels. This persists in the multivariable model, indicating an association over and above that already known to exist between anxiety and low socio-economic status (16, 17). This may reflect the findings of Ussher et al that CHD patients with low health literacy have increased difficulty understanding information, less knowledge of heart problems, and increased discomfort about asking for explanations (18). The finding in the univariable analysis that patients with low health literacy had more contact with practice nurses but not with other health services requires further investigation.

# Study limitations

As a cross-sectional study this project cannot demonstrate causality or the impact of low health literacy over time.

Our findings may underestimate of the true picture; the 14.45% of participants who declined to do the REALM share the characteristics of people with low health literacy and may have declined because of reading difficulties.

Our findings of more frequent, and longer, GP practice nurse consultations should be interpreted with caution, as this was found during univariable analysis with no other factors controlled for; no service use data were entered into the multivariable model. The above preliminary finding thus requires more detailed health economic analysis and interpretation.

Finally, the REALM, although highly correlated with tests of functional health and general literacy, is not itself a test of functional skills but of pronunciation.

# Summary

Our findings indicate that there is a disadvantaged group of people on GP CHD registers who have low health literacy in addition to other socio-demographic barriers to health. A new finding is that these people have significantly higher anxiety levels than people with adequate health literacy.

# Next steps

Our possible finding that people on GP CHD registers with lower health literacy consulted practice nurses more frequently will inform future Up-Beat pilot interventions (10) and our longitudinal cohort data will enable us to explore the impact of low health literacy on patients on GP CHD registers, and on their health service use.

# Acknowledgements

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# **Data Sharing Statement**

There are no additional unpublished data from this study.

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None

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Characteristics of people with low health literacy on coronary heart disease GP registers in South London Lead, corresponding author and paper guarantor

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#### Contributions:

GR Led on development of the research idea, contributed to interpretation of result, and led on writing the paper

AM collected research data and contributed to interpretation of results and writing the paper

SH collected research data and contributed to interpretation of results and writing the paper

RP led on statistical analysis of the data and interpretation of the results PW conducted additional statistical analysis and contributed to the paper AM co-developed the UPBEAT cohort study in which the study is sited, contributed to the research idea, contributed to interpretation of results and writing the paper

AS contributed to the project design, analysis of results and writing the paper PW contributed to the research idea, interpretation of the results and writing the paper

AT led on the development of the UPBEAT cohort study in which the study is sited, contributed to the research idea, contributed to interpretation of results and writing the paper.

All authors have approved the final version

#### Abstract (299 words)

Objective. To explore characteristics associated with, and prevalence of, low health literacy in patients recruited to investigate the role of depression in patients on General Practice (GP) Coronary Heart Disease (CHD) registers (the Up-Beat UK study).

Design. Cross-sectional cohort. The health literacy measure was the Rapid Estimate of Health Literacy in Medicine (REALM). Univariable analyses identified characteristics associated with low health literacy and compared health service use between health literacy statuses. Those variables where there was a statistically significant/borderline significant difference between health literacy statuses were entered into a multivariable model.

Setting. 16 general practices in south London, UK.

Participants: Inclusion: patients >18 years, registered with a GP and on a GP CHD register. Exclusion: patients temporarily registered.

Primary outcome measure: REALM.

Results. Of the 803 Up-Beat cohort participants, 687 (85.55%) completed the REALM of whom 106 (15.43%) had low health literacy. Twenty-eight participants could not be included in the multivariable analysis due to missing predictor variable data, leaving a sample of 659. The variables remaining in the final model were age, gender, ethnicity, IMD score, years of education, employment; BMI and alcohol intake, and anxiety scores (Hospital Anxiety and Depression Scale (HADS). Univariable analysis also showed that people with low health literacy may have more, and longer, practice nurse consultations than people with adequate health literacy.

Conclusions. There is a disadvantaged group of people on GP CHD registers with low health literacy. The multivariable model showed that patients with low health literacy have significantly higher anxiety levels than people with adequate health literacy. In addition, the univariable analyses show that such patients have more, and longer, consultations with practice nurses. We will collect 4-year longitudinal cohort data to explore the impact of health literacy in people on GP CHD registers and the impact of health literacy on health service use.

# Article summary

#### **Article focus**

  Identifying the prevalence and characteristics of people with CHD and low health literacy on coronary heart disease GP registers in South London, UK

# **Key Messages**

- The characteristics of patients with low health literacy on UK GP CHD registers are similar to those seen in other long-term conditions in studies undertaken in other industrialised countries
- The prevalence of low health literacy to be close to that predicted from national general literacy levels at 15%
- People on GP CHD registers who have higher anxiety levels are more likely to have low health literacy than people with lower anxiety levels

# **Strengths**

- The data were collected within a prospective cohort study
- There were a wide range of sociodemographic data collected enabling characteristics of patients with low health literacy to be described
- The simultaneous collection of psychological and service use data enabled these to be compared between patients with low and adequate health literacy

#### Limitations

- As a cross-sectional study this project cannot demonstrate causality or the impact of low health literacy over time.
- The findings may underestimate of the true picture; the participants who declined to do the REALM may have declined because of reading difficulties.
- Our findings of more frequent, and longer, GP practice nurse consultations should be interpreted with caution; the above preliminary finding requires more detailed health economic analysis and interpretation
- The REALM, although highly correlated with tests of functional health and general literacy, is not itself a test of functional skills but of pronunciation

#### Introduction

Health literacy, 'the cognitive and social skills that determine the motivation and ability of individuals to (access), understand and use information in ways that promote and maintain good health' (1) is a social determinant of health (2). Whilst associated with other social determinants e.g. ethnicity, income, education, and socio-demographic status (SES), it has an independent association with poor health (3). International comparisons of health literacy levels are hampered by differing national definitions; however it is clear that health literacy is an important issue in many industrialised nations. The proportion of the population thought to be disadvantaged through low health literacy ranges from 19% in the US (4) to 55% in Canada (5). A recent survey of health literacy in Europe, where a common definition of health literacy was adopted, shows a range of health literacy skills between nations, with the proportion of the population having suboptimal health literacy skills ranging from 27.3% in the Netherlands to 61.4% in Bulgaria (6). There are no data on health literacy levels in England; however the 2011 national skills survey has shown that 15% of the adult population (=5 million people) are 'functionally illiterate' (7) (i.e. have insufficient literacy skills to achieve their potential in life and society (8)). It is reasonable to assume that a similar proportion also have low health literacy.

Low health literacy has greatest impact in complex health conditions when patients have to understand procedures, manage medication, and attend multiple appointments. US studies have shown that adults with low health literacy have a higher prevalence of diabetes and heart failure, worse physical and mental health, and higher all-cause mortality (9). There is little research on low health literacy and coronary heart disease (CHD), prompting us to explore this within a longitudinal cohort of patients recruited to investigate the role of depression in patients on General Practice (GP) CHD registers (10). This short report presents initial findings on the prevalence and characteristics of people with CHD and low health literacy.

#### Method

The design, recruitment, power calculation, and measures used in the Up-

Beat cohort study are described elsewhere (10). The study was granted ethical approval by the Bexley and Greenwich Research Ethics Committee (REC Reference: 07/H0809/38) (10). Health literacy was measured using the Rapid Estimate of Health Literacy in Medicine (REALM) (11), a 66-item health word pronunciation test highly correlated with other measures of health literacy (12, 13) and widely used in research studies (3). The version of the REALM validated for use in the UK was used. This groups people into 'low' and 'adequate' health literacy with people with a score of < 59 out of the possible 66 being considered to have low health literacy (14).

<u>Study design.</u> A cross-sectional analysis of baseline data from the Up-Beat UK Cohort Study (10).

#### Statistical Analysis

 Initial exploratory univariable analysis was undertaken to identify factors independently associated with low health literacy using  $\chi^2$  tests (categorical variables) and t-tests (continuous variables). Multivariable regression analysis was then undertaken to identify those factors that remained significant when all those identified in the univariable analysis were considered together. Those characteristics where there was a statistically significant (p < 0.05) or borderline significant difference between people with low and adequate health literacy were entered into the multivariable model; logistic regression was used to model predictors of low health literacy. The fit for the model was assessed by the C statistic (ROC curve) and the Hosmer-Lemeshow goodness of fit  $\chi^2$  test.

Analyses were performed using Stata version 11.2.

#### Results

Cohort characteristics are detailed elsewhere (10). Cohort recruitment and a study flow diagram are shown in figure 1.

Figure about here.

The results of the univariable and multivariable analyses are shown in table 1.

**Table: Characteristics by Health Literacy** 

		Health L	iteracy			
		Adequate	Low			
		raoquato	20	Univariable	Multiv	ariable
		N (%)	N (%)	analysis		lysis
Total		581 (84.57)	106 (15.43)	N=687	N=659	
				P-value (1)		d odds o ow healtl p-values
	Soc	io-demographic	characteristics		•	
Gender	Male	397 (68.33)	87 (82.08)	0.004	0.32 (<0.001)	
	Female	184 (31.67)	19 (17.92)			
	White	524 (90.19)	81 (76.42)	<b>-0.001</b>		
Ethnicity	Other	57 (9.81)	25 (23.58)	<0.001	3.12 (<	0.001)
Age, Mean (SD)	Years	71.14 (10.41)	68.92 (11.84)	0.049	1.00 (	(0.873)
Index of Multiple Deprivation score, Mean (SD) Time in	Range 0-100 Years	18.34 (13.84) 12.01 (3.40)	24.37 (13.24) 10.92 (2.46)	<0.001 <0.001 <sup>(2)</sup>		(0.072)
education, Mean (SD)					0.84 (0.001)	
Employment	Unemployed/stude	14 (2.42)	10 (9.52)	0.001		
status	nt					0.400
	Paid employment	117 (20.21)	18 (17.14)		0.31	0.138
	Retired/ Housewife	448 (77.37)	77 (73.33)		0.34	
		Lifestyle Chara				
Alcohol intake	Doesn't drink	136 (23.45)	44 (41.90)	0.001		0.002
(Units)	1-10 units	289 (49.83)	44 (41.90)		0.48	
	11-20 units	87 (15.00)	9 (8.57)		0.34	
	Greater than 21units	68 (11.72)	8 (7.62)		0.24	
ВМІ	Underweight/ Normal	145 (25.62)	15 (14.29)	0.024		0.027
	Overweight	250 (44.17)	48 (45.71)		2.38	
	Obese	171 (30.21)	42 (40. 00)		2.50	
		Mental He			1	
Depression score, M	Mean (SD)	2.86 (3.14)	4.28 (3.76)	<0.001 (2)		
Anxiety score, Mean (SD)		4.39 (4.13)	6.35 (5.18)	<0.001 (2)	1.08 (	(0.002)
. <b>y</b>	11 10 00	sation in the 6 m	41 1 4 1		1	,
Number of practice (SD)		0.89 (1.85)	1.33 (2.21)	0.008 (3)		
Duration of practice nurse visit, Mean (SD)		4.98 (7.05)	6.98 (8.30)	0.008 (3)		
All other service use variables (4)				0.120 <sup>(5)</sup> - 0.793 <sup>(6)</sup>		
15	t for continuous variab	loo and ahi aawar	d tooto for ootog		ı	

<sup>&</sup>lt;sup>2</sup> Unequal variances t-test used

<sup>&</sup>lt;sup>3</sup> Wilcoxon rank sum test

<sup>&</sup>lt;sup>4</sup> Number of Accident and Emergency visits, Day hospital and in-patient admissions (days), outpatient visits, GP visits (number, duration), district nurse visits (number, duration), other medical visits (number, duration), other care based visits (number, duration), informal care visits number).

<sup>&</sup>lt;sup>5</sup> Number of Accident and Emergency visits

<sup>&</sup>lt;sup>6</sup> Other care based visits (duration)

Of the 803 cohort participants 687 (85.55%) completed the REALM questionnaire. The 116 non-responders were excluded from the analyses. Non-responders lived in more socio-economically deprived areas and had received fewer years of education than those who completed the REALM. There was no difference in ethnicity (responders vs. non-responders).

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Exploratory univariable analyses showed that people with low health literacy were more likely to be male, from a non-white ethnic group, live in a more deprived area, have spent fewer years in education, and were less likely to be employed. Age was borderline significant with people with low health literacy being slightly younger than people with adequate health literacy (difference in mean age between groups 2.22 years).

The variables remaining in the final multivariable model were age, gender, ethnicity (white versus other), IMD score, years of education, employment; BMI and alcohol intake, and anxiety scores (Hospital Anxiety and Depression Scale (HADS)) (15). There was an 8% increase in the odds of low health literacy for every single unit increase in the anxiety score on HADS (range 0-21).

Service use analysis (univariable only) showed that people with low health literacy had significantly more, and longer, GP practice nurse consultations than people with adequate health literacy, but other service use showed no differences between groups.

# **Discussion**

 Key findings

This study confirms that the characteristics of patients with low health literacy on UK GP CHD registers are similar to those seen in other long-term

conditions in studies undertaken in other industrialised countries (i.e., membership of a minority ethnic group, socio-economic deprivation, fewer years in education, and lower income (9)). In contrast to other studies (3-6), the patients with low health literacy in our study were slightly younger than the patients with adequate health literacy, although the difference between groups was small and should be interpreted with caution. We found the prevalence of low health literacy to be close to that predicted from national general literacy levels (7).

In addition people on GP CHD registers who have higher anxiety levels are more likely to have low health literacy than people with lower anxiety levels. This persists in the multivariable model, indicating an association over and above that already known to exist between anxiety and low socio-economic status (16, 17). This may reflect the findings of Ussher et al that CHD patients with low health literacy have increased difficulty understanding information, less knowledge of heart problems, and increased discomfort about asking for explanations (18). The finding in the univariable analysis that patients with low health literacy had more contact with practice nurses but not with other health services requires further investigation.

#### Study limitations

As a cross-sectional study this project cannot demonstrate causality or the impact of low health literacy over time.

Our findings may underestimate of the true picture; the 14.45% of participants who declined to do the REALM share the characteristics of people with low health literacy and may have declined because of reading difficulties.

Our findings of more frequent, and longer, GP practice nurse consultations should be interpreted with caution, as this was found during univariable analysis with no other factors controlled for; no service use data were entered into the multivariable model. The above preliminary finding thus requires more detailed health economic analysis and interpretation.

Finally, the REALM, although highly correlated with tests of functional health and general literacy, is not itself a test of functional skills but of pronunciation.

# Summary

Our findings indicate that there is a disadvantaged group of people on GP CHD registers who have low health literacy in addition to other socio-demographic barriers to health. A new finding is that these people have significantly higher anxiety levels than people with adequate health literacy.

# Next steps

Our possible finding that people on GP CHD registers with lower health literacy consulted practice nurses more frequently will inform future Up-Beat pilot interventions (10) and our longitudinal cohort data will enable us to explore the impact of low health literacy on patients on GP CHD registers, and on their health service use.

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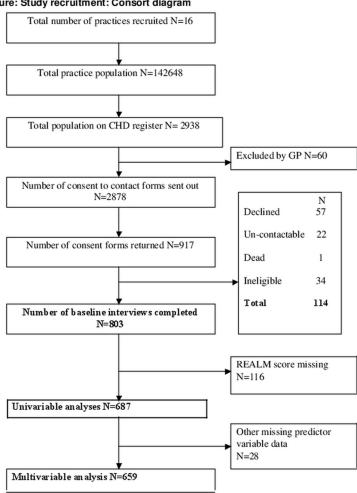
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# Exploring indicators of low health literacy in a cohort with symptomatic **Coronary Heart Disease**

#### Figure: Study recruitment: Consort diagram



90x125mm (300 x 300 DPI)