

# **Sharing electronic health records with patients: Who is using the Care Information Exchange portal? A cross-sectional study.**

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# Sharing electronic health records with patients: Who is using the Care Information Exchange portal? A cross-sectional study.

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## Abstract

**Background:** Sharing electronic health records with patients has been shown to improve patient safety and quality of care, and patient portals represent a powerful and convenient tool to enhance patient access to their own healthcare data. However, adoption rates vary widely across countries and, within countries, across regions and health systems. A better understanding of the characteristics of users and non-users is critical to understand which groups remain underserved or excluded from using such tools.

**Objective:** To identify the determinants of usage of the Care Information Exchange (CIE), a shared patient portal program in the United Kingdom.

**Methods:** A cross-sectional study was conducted, using an online questionnaire. Individual-level data from patients registered in the CIE portal were collected, including age, gender, ethnicity, educational level, health status, postcode, and digital literacy (using the eHEALS tool). Registered individuals were defined as having an account created in the portal, independent of their actual use of the platform, and users were defined as having ever used the portal. Multivariate logistic regression was used to model the probability of being a user. Statistical analysis was performed in R, and Tableau ® was used to create maps of the proportion of CIE users by postcode area.

**Results:** A total of 1,083 subjects replied to the survey (+186% of the estimated minimum target sample). The proportion of users was 61.6% (n=667), and within these, the majority (57.7%, n=385) used the portal at least once a month. To characterise the users and non-users of the system, we performed a sub-analysis of the sample, including only participants that have provided at least information regarding gender and age category. The sub-analysis included 650 individuals (59.8% women, 84.8% over 40 years). The majority of the subjects were white (76.6%, n=498), resident in London (64.7%, n=651), and lived in North West London (55.9%, n=363). Individuals with a higher educational degree (undergraduate/professional or postgraduate/higher) had higher odds of being a portal user (adjusted OR = 1.58 (95%CI [1.04 - 2.39]), and 2.38 (95%CI [1.42 - 4.02], respectively), compared to those with a secondary degree or below. Higher digital literacy scores (<30) were also associated with higher odds of being a user (adjusted OR = 2.96 (95%CI [2.02 - 4.35])). Those with a good overall health status had lower odds of being a user (adjusted OR = 0.58 (95%CI [0.37 - 0.91])).

**Conclusions:** This work adds to the growing body of evidence highlighting the importance of educational aspects (educational level and digital literacy) in the adoption of patient portals. It is critical that further research not only describes, but also systematically addresses these inequalities through patient-centred interventions aiming to reduce the digital divide. Healthcare providers and policymakers must partner in investing and delivering strategic programs that improve access to technology and

digital literacy, in an effort to improve digital inclusion and reduce inequities in delivery of care. Clinical Trial: Not applicable.

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## Original Manuscript

## Original Paper

# Sharing electronic health records with patients: Who is using the Care Information Exchange portal? A cross-sectional study.

## Abstract

**Background:** Sharing electronic health records with patients has been shown to improve patient safety and quality of care, and patient portals represent a powerful and convenient tool to enhance patient access to their own healthcare data. However, the success of portals will only be possible through sustained adoption by its end-users: patients. A better understanding of the characteristics of users and non-users is critical to understand which groups remain underserved or excluded from using such tools.

**Objective:** To identify the determinants of usage of the Care Information Exchange (CIE), a shared patient portal program in the United Kingdom.

**Methods:** A cross-sectional study was conducted, using an online questionnaire. Information collected included age, gender, ethnicity, educational level, health status, postcode and digital literacy. Registered individuals were defined as having had an account created in the portal, independent of their actual use of the platform; users were defined as having ever used the portal. Multivariate logistic regression was used to model the probability of being a user. Statistical analysis was performed in R, and Tableau ® was used to create maps of the proportion of CIE users by postcode area.

**Results:** A total of 1,083 subjects replied to the survey (+186% of the estimated minimum target sample). The proportion of users was 61.6% (n=667), and within these, the majority (57.7%, n=385) used the portal at least once a month. To characterise the users and non-users of the system, we performed a sub-analysis of the sample, including only participants that had provided at least information regarding gender and age category. The sub-analysis included 650 individuals (59.8% women, 84.8% over 40 years). The majority of the subjects were white (76.6%, n=498), resident in London (64.7%, n=651), and lived in North West London (55.9%, n=363). Individuals with a higher educational degree (undergraduate/professional or postgraduate/higher) had higher odds of being a portal user (adjusted OR = 1.58 (95%CI [1.04 - 2.39]), and 2.38 (95%CI [1.42 - 4.02], respectively), compared to those with a secondary degree or below. Higher digital literacy scores ( $\geq 30$ ) were also associated with higher odds of being a user (adjusted OR = 2.96 (95%CI [2.02 - 4.35])). Those with a good overall health status had lower odds of being a user (adjusted OR = 0.58 (95%CI [0.37 - 0.91])).

**Conclusion:** This work adds to the growing body of evidence highlighting the importance of educational aspects (educational level and digital literacy) in the adoption of patient portals. It is critical that further research not only describes, but also systematically addresses these inequalities through patient-centred interventions aiming to reduce the digital divide. Healthcare providers and policymakers must partner in investing and delivering strategic programs that improve access to technology and digital literacy, in an effort to improve digital inclusion and reduce inequities in delivery of care.

**Keywords:** patient portals; electronic health records; patient participation.

## Introduction

A growing body of evidence supports providing patients access to their electronic health records in order to improve several aspects of quality of care, including patient safety [1–3], patient-centredness [4–5] and effectiveness [3]. Patient portals are currently recognised as a promising mechanism to improve healthcare data sharing with patients. Patients may use portals for a range of purposes, including to enter, retrieve or share their healthcare information; to communicate with their healthcare providers, and to self-manage their health [6]. The use of patient portals can improve health outcomes (for instance, in the case of type 2 diabetes) [7–8] increase patient satisfaction [9], improve medication safety and adherence [10–12] and communication between the patient and the healthcare provider [9–13].

The success of patient portals and the subsequent achievement of their proposed benefits will only be possible through sustained adoption by its end-users: the patients. However, questions remain about how healthcare providers and policy makers can encourage sustainable adoption by patients, without exacerbating the pre-existing digital divide, or widening discrepancies in the delivery of care [14]. Infact, despite the increasing implementation of patient portals by healthcare institutions and governments worldwide, adoption by patients has remained slower than expected [15–16]. A meta-analysis published by Fraccaro P et al (2017) including 40 studies showed an overall mean adoption rate of 52% (95%CI 42 to 62%) [17]. However, the authors emphasise that evaluation of adoption in clinical practice may give different results from those obtained in RCTs [17].

Several individual and socio-technical factors were suggested to affect portal adoption such as age, health status, educational level, and patient activation (i.e., the knowledge, skills and confidence a person has in managing their own health and care) [18–20]. While there is some evidence of higher adoption by those with a poorer health status [21–22] and higher educational level [20], there is mixed evidence about the impact of age [21,23] and patient activation [24,25]. Technology-related factors may also play an important role, with higher digital health literacy, good portal design, and a higher perceived usefulness and use of ease being potentially associated with a positive impact [26].

In 2015, Patients Know Best (PKB) teamed up with Imperial College NHS Healthcare Trust to roll out the ‘Care Information Exchange’ (CIE) across Northwest London (NWL) – the largest shared patient portal program in the UK - hosting the records of over 2.3 million people living in North West London [27]. The CIE collects data from hospitals and GP practices in NWL, and 15 other hospitals outside of North West London including Birmingham, Bristol, Liverpool, Manchester, Scotland and Wales [27]. CIE was the first to introduce ‘mass registration’, enabling people to sign up and access their health record at scale and with speed in a number of ways: either by speaking to a member of staff; by using the kiosk check-in screen commonly found in hospital outpatient waiting rooms; or by letter of invitation to their home. The CIE contains patient information including appointment details, test results, care plans, discharge summaries, clinical letters, and information on medications. If a patient’s primary care practice has signed up, data such as allergies, medications, and diagnoses will also be visible to them. Patients may access their records whenever they wish to review information or when notified about new information such as test results being available [3].

This study aimed to characterise individuals registered with the CIE and explore the differences between users and non-users in terms of their demographic, geographic, health status, and educational characteristics (i.e., educational level and digital health literacy), and motivation to be involved in their own healthcare (as a proxy measure for patient activation), thus identifying the main determinants of usage of the portal. Our hypothesis is that the users’ characteristics described above can affect the adoption of CIE. This is key to understanding barriers to adoption, as well as understanding which groups remain underserved or excluded from using patient portals, critical for a future patient-centred digital healthcare delivery.

## Methods

### Study design, participants and data collection

We conducted a cross-sectional study, using an online anonymous questionnaire presented via Qualtrics.

Patients registered with the CIE portal and who had logged at least once during the time of study (n=27,411) were invited to follow the link to complete the survey. There were no specific exclusion criteria, however, patients need to be 18 years or older to register to use the portal. This link contained general information about the purpose of the survey and informed consent was sought at the beginning of the survey. Considering this population, a confidence level of 95% and a margin of error of 5%, the minimum sample size to ensure representativeness was calculated as n=379 respondents. The survey was open for completion between July 1st, 2018, and July 1st, 2019. No patient identifiers were collected. Information collected included age, gender, ethnicity, educational level, postcode (first part), digital literacy, health status, and motivation to be involved in their own healthcare (as a proxy for patient activation).

### Measurements

Age was categorised into age bands (<30; [31-40]; [41-50]; [51-65]; ≥65), and ethnicity was categorised into white or Black, Asian, and minority ethnic (BAME). The first part of the postcode was categorised as London's official postal districts for descriptive purposes [28]. For the univariate and multivariate analysis, due to the highly skewed distribution toward West and NWL, postcode areas were categorised as West London, NWL, other London, or other.

Digital literacy was assessed using the eHealth Literacy Scale (eHEALS), developed by Norman and Skinner [29]. This tool identifies six core skills or literacies: (1) traditional literacy, (2) health literacy, (3) information literacy, (4) scientific literacy, (5) media literacy, and (6) computer literacy. Based on these core literacies, the eHEALS tool assesses consumers' knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems. The eHEALS tool uses a 5-point Likert scale (1-strongly disagree, 5-strongly agree), and the score ranges from 8 to 40, with a higher score indicating higher literacy.

Overall health status was assessed via a multiple-choice question ("How good do you think your health is?" with possible responses: "Very good", "Somewhat good", "Neither good nor poor", "Somewhat poor", "Very poor"). Motivation to be involved in their own care was similarly assessed via multiple choice ("In general, how motivated to be involved in your healthcare are you?" with possible responses: "A little", "A moderate amount", "A lot", "Very much").

Registered individuals were defined as having had an account created in the CIE portal, independent of their actual use of the platform. "Users" and "non-users" were defined as individuals having answered "Yes" or "No", respectively, to the question "Have you ever used CIE?". Those who answered "Yes" (i.e., users) were also asked about their frequency of use ("How often do you use CIE?" with response options as follows: "Less than once a month", "Once a month", "Once a week", "Twice a week or more.")



## Data analysis

Means and standard deviations (SDs) were calculated for continuous variables; proportions and counts were calculated for categorical variables. Univariate logistic regression modelled the odds of being a user, as a function of each individual predictor. The resulting coefficients, expressed as log(odds) ratios, were transformed to crude odds ratios (ORs) with a 95% confidence interval.

Multivariate logistic regression was used to model the probability of being a user, as a function of age, gender, educational level, digital literacy (categorical variables), and overall health status. The variables were chosen for the multivariate analysis through automated, backwards stepwise elimination. With this procedure, all variables of interest are included in the first iteration of the model, and are removed one by one, starting with the ones whose elimination would improve the model fit most, and ending the process when removing an additional variable worsens the model fit. Model quality comparisons were conducted using the Akaike Information Criterion [30]. Basic demographic variables (age and gender) were inputted as forced-in covariates in the multivariate analysis. Adjusted odds ratios with a 95 percent confidence interval were calculated.

Statistical analyses were conducted in RStudio, using the 'plyr', 'dplyr', 'ggplot2', and 'car' packages. Tableau® software was used to create maps of the total number of participants, and the proportion of CIE users by postcode area.

## Ethics

The study was approved as a Service Evaluation at Imperial College Healthcare NHS Trust (Registration Number: 296/2018).

## Results

### Participants' characteristics

The survey link was shared with a total of 27,411 patients that logged on at least once (i.e., were accredited to use the system) between July 1st, 2018 and July 1st, 2019. A total of 1,083 subjects replied to the survey (+186% of the estimated target sample). Of these, 650 participants provided information regarding their gender and age, and we limited the analysis to these individuals (+71.5% of the estimated target sample). The proportion of users was 61.6% (n=667), and within these, more than half (57.7%, n=385) used the portal at least once a month.

Self-identified users and non-users of CIE were more likely to provide demographic information (for age: 37.6% and 36.5%, respectively; for gender: 36.9% and 36.6%, respectively), than survey respondents who did not answer questions regarding CIE use (25.9% and 26.5%, respectively).

In the subanalysis of patients that provided basic characterisation regarding gender and age category, 59.8% were women and 84.8% were aged over 40 years. The majority of the subjects were white (76.6%, n=498) and resided in London (64.7%, n=651). Amongst these, 55.9% were from NWL (n=363). A more detailed overview of the distribution of the subjects by postcode area is provided in Figure 1. The mean literacy score assessed by the eHEALS tool was 31.5 (SD=7.9), and 22.3% (n=145) had a postgraduate degree or higher. Most participants considered themselves to be very motivated to be involved in their own care (57.5%, n=374), and 41.8% (n=272) considered themselves to have a good or very good health status. A full description of the analysed sample, as well as characteristics of the non-user and user groups, is provided in Table 1.

Table 1. Characteristics of the participants according to their use of the system (N=650)

Characteristics	Non-users (n = 205)	Users (n=447)	Total (n=650)
<b>Gender, n (%)<sup>a</sup></b>			
Female	113 (29.0)	276 (71.0)	389 (59.8)
Male	91 (35.3)	167 (64.7)	258 (39.6)
Other	1 (0.33)	2 (0.67)	3 (0.4)
No response	-	-	-
<b>Age band, n (%)<sup>a</sup></b>			
<30	9 (29.0)	22 (71.0)	31 (4.7)
31-40	20 (29.4)	48 (70.6)	68 (10.5)
41-50	23 (27.1)	62 (72.9)	85 (13.1)
51-65	72 (30.3)	166 (69.7)	238 (36.6)
≥ 65	81 (35.5)	147 (64.5)	228 (35.1)
No response	-	-	-
<b>Ethnicity, n (%)<sup>a</sup></b>			
BAME	34 (31.2)	75 (68.8)	109 (16.8)
White	155 (31.1)	343 (68.9)	498 (76.6)
Other	16 (42.1)	22 (57.9)	38 (5.8)
No response	0 (0)	5 (100)	5 (0.8)
<b>Geographic location, n (%)<sup>a</sup></b>			
London			
East	2 (50)	2 (50)	4 (0.6)
East Central	0 (0)	0 (0)	0 (0.0)
North	0 (0)	7 (100)	7 (1.1)
North West	15 (27.3)	40 (72.7)	55 (8.5)
South East	0 (0)	5 (100)	5 (0.7)
South West	20 (41.7)	28 (58.3)	48 (7.4)
West	96 (32.1)	203 (67.9)	299 (46.0)
West Central	1 (50)	1 (50)	2 (0.3)
Other	62 (29.8)	146 (70.2)	208 (31.8)
No Response	9 (40.9)	13 (59.1)	22 (3.5)

<b>Educational degree, n (%)<sup>a</sup></b>			
Secondary school or below	75 (38.8)	118 (61.1)	193 (29.7)
Undergraduate or professional degree	77 (30.0)	180 (70.0)	257 (39.5)
Postgraduate or higher	33 (22.8)	112 (77.2)	145 (22.3)
No response	20 (36.4)	35 (63.6)	55 (8.5)
<b>Digital literacy (eHEALS score), mean (SD)</b>	28.4 (8.1)	32.9 (7.4)	31.5 (7.9)
<b>Overall health status, n (%)<sup>a</sup></b>			
Good or very good	95 (34.9)	177 (65.1)	272 (41.8)
Neither good nor poor	55 (34.2)	106 (65.8)	161 (24.8)
Poor or very poor	55 (25.3)	162 (74.7)	217 (33.3)
No response	-	-	-
<b>Motivation to be involved in own care, n (%)<sup>a</sup></b>			
Not very much	7 (53.8)	6 (46.2)	13 (2.0)
A moderate amount	40 (48.2)	43 (51.8)	83 (12.7)
A lot	61 (34.5)	116 (65.5)	177 (27.2)
Very much	96 (25.7)	278 (74.3)	374 (57.5)
No response	1 (0.33)	2 (0.67)	3 (0.5)

<sup>a</sup> Percents may not sum to 100 due to rounding.

### *Differences between users and non-users*

Characteristics of both users and non-users were explored using univariate logistic regression (crude ORs) and a logistic regression model with predictors (adjusted ORs). The differences between groups are shown in Table 2.

Crude ORs showed that individuals with a higher educational degree (undergraduate/professional or postgraduate/higher) had higher odds of being a portal user (crude OR = 1.48 (95%CI [1.00 - 2.20] and 2.15 (95%CI [1.33 - 3.05], respectively) compared to those with a secondary degree or below. Higher digital literacy scores (>30) were also associated with higher odds of being a user (crude OR = 2.90 (95%CI [2.06 - 4.11]), as well as those that reported being 'very much motivated to be involved in their own care (crude OR = 3.38 (95%CI [1.10 -10.3]). Participants with a good overall health status had lower odds of being a user (crude OR = 0.63 (95%CI [0.43 - 0.94]).

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The adjusted ORs represent the multivariate analysis of predictors of CIE use. Initially, all variables were included in the multivariate model, and backward stepwise elimination was used to select the best-fit model. Digital literacy, education, and health status remained in the naive best fit regression, and gender and age were re-inputted as forced-in covariates, as previously described in the methods. Sensitivity analyses showed minimal differences as a result of their inclusion or exclusion. All covariates that were statistically significant in the naive model remained so, and no additional

variables gained significance.

Adjusted ORs show that individuals with a higher educational degree (undergraduate/professional or postgraduate/higher) had higher odds of being a portal user (adjusted OR = 1.58 (95%CI [1.04 - 2.39] and 2.38 (95%CI [1.42 - 4.02], respectively) compared to those with a secondary degree or below. Higher digital literacy scores ( $\geq 30$ ) were also associated with higher odds of being a user (adjusted OR = 2.96 (95%CI [2.02 - 4.35]). Those with a good overall health status had lower odds of being a user (adjusted OR = 0.58 (95%CI [0.37 - 0.91]).

A significant association was found with “increased motivation to be involved in own care” (crude OR for those very motivated to be involved in own care = 3.38 (95%CI [1.10-10.3]), but it was not possible to explore the effect in multivariate analysis, since the variable was removed from the best-fit model as part of the stepwise backwards elimination procedure. No significant associations were found with age, gender, ethnicity, or geographic location.

Table 2. Characteristics of users (N=650) according to their input with crude and adjusted odds ratios

	Non-adjusted model <sup>(a)</sup>		Adjusted model <sup>(b)</sup>	
	Crude OR (95% CI)	<i>P</i>	Adjusted OR (95% CI)	<i>P</i>
<b>Gender</b>				
Female	[Reference]	-	[Reference]	-
Male	0.75 (0.54 - 1.05)	0.096	0.92 (0.624 - 1.35)	0.665
Other	0.81 (0.07 - 9.12)	0.871	0 (0 - Inf)	0.978
<b>Age band</b>				
<30	[Reference]	-	[Reference]	-
31-40	0.98 (0.39 - 2.50)	0.969	0.63 (0.22 - 1.76)	0.373
41-50	1.10 (0.44 - 2.74)	0.833	0.88 (0.32 - 2.40)	0.798
51-65	0.94 (0.41 - 2.15)	0.889	0.85 (0.34 - 2.12)	0.725
$\geq 65$	0.74 (0.33 - 1.69)	0.477	0.65 (0.26 - 1.65)	0.370
<b>Ethnicity, n (%)<sup>c</sup></b>				
White	[Reference]	-	_(c)	_(c)
BAME / Other	0.88 (0.59 - 1.33)	0.551	_(c)	_(c)

<b>Geographic location<sup>c</sup></b>				
West London	0.94 (0.65 - 1.36)	0.739	_( <sup>c</sup> )	_( <sup>c</sup> )
North West London	1.19 (0.62 - 2.29)	0.405	_( <sup>c</sup> )	_( <sup>c</sup> )
Other London	0.85 (0.47 - 1.53)	0.594	_( <sup>c</sup> )	_( <sup>c</sup> )
Other	[Reference]	-	_( <sup>c</sup> )	_( <sup>c</sup> )
<b>Educational degree</b>				
Secondary or below	[Reference]	-	[Reference]	-
Undergraduate / professional	1.48 (1.00 - 2.20)	0.049	1.58 (1.04 - 2.39)	0.001
Postgraduate or higher	2.15 (1.33 - 3.50)	0.002	2.38 (1.42 - 4.02)	0.032
<b>Digital literacy, n (%)</b>				
Literacy score < 30	[Reference]	-	[Reference]	-
Literacy score ≥ 30	2.90 (2.06 - 4.11)	>.001	2.96 (2.02 - 4.35)	>.001
<b>Overall health status, n (%)</b>				
Poor	[Reference]	-	[Reference]	
Neutral	0.65 (0.42 - 1.02)	0.063	0.73 (0.45 - 1.20)	0.210
Good	0.63 (0.43 - 0.94)	0.023	0.58 (0.37 - 0.91)	0.016
<b>Motivation to be involved in own care, n (%)<sup>(c)</sup></b>				
Not very much	[Reference]	-	_( <sup>c</sup> )	_( <sup>c</sup> )
A moderate amount	1.25 (0.39 - 4.05)	0.168	_( <sup>c</sup> )	_( <sup>c</sup> )
A lot	2.22 (0.71 - 6.89)	0.705	_( <sup>c</sup> )	_( <sup>c</sup> )
Very much	3.38 (1.10 - 10.3)	0.032	_( <sup>c</sup> )	_( <sup>c</sup> )

<sup>a</sup>Crude odds ratios calculated from univariate logistic regression where the probability of being a user was modelled. <sup>b</sup>Logistic regression model with predictors: age, gender, education level, digital literacy, and health status. <sup>c</sup> These variables were removed from the multivariate analysis using a stepwise backwards elimination procedure.

## Discussion

### Summary of key findings

Participants with an undergraduate or professional degree were 58% more likely to use the portal than those with a secondary education or below (adjusted OR = 1.58 (95%CI [1.04 - 2.39]), and those with a postgraduate degree were more than two times as likely to use the portal (adjusted OR = 2.38 (95%CI [1.42 - 4.02])). People with an eHEALS digital literacy score greater than 30 were nearly 3 times more likely to be a portal user than those with eHEALS score below 30 (adjusted OR = 2.96 (95%CI [2.02 - 4.35])). These results expose the impact of education and literacy on the adoption of digital technologies and reinforces their role as drivers of patient exclusion.

Participants with good overall health status were about half as likely to have reported using the portal compared to those reporting poor health status (adjusted OR = 0.58 (95%CI [0.37 - 0.91])). This reinforces that whilst the ability to use digital technologies is an important contributor to their adoption, so too is the perceived need for the service. People in poor health will have more incentive to engage with technologies that facilitate their health care than those without health challenges.

No significant associations were found with age, gender, ethnicity, geographic location, or motivation to be involved in their own care. The fact that demographic factors such as these were not strongly associated with usage points further to the conclusion that ability and need to use digital health management tools are potentially the key drivers of their uptake.

### Comparison with previous literature

Our findings are consistent with previous evidence suggesting that portal users, compared to non-users, are more often highly educated and have higher eHealth literacy levels [31].

The spread and scale of digitally-enabled care is happening fast - in fact, faster than our ability to ensure that all patient groups have the basic digital literacy tools to fully exploit its potential. Educational level seems to be an independent predictor of portal usage: in an inpatient study, after adjustment for age, gender, race/ethnicity, immigration status, educational attainment, and employment status, those without an education degree had higher odds of never logging on to the portal [20].

Previous studies have also found that patients with higher eHealth literacy levels have a higher likelihood of being a portal user [32-33]. Importantly, people's self-perceived skills to use online information actually have an impact on their health and the quality of the care received, and that a lack of such skills may result in adverse health outcomes [34-35]. According to Holt KA et al (2019), the information about patients' health literacy may provide a better understanding of patients' reasons for not using digital health services, rather than sociodemographic data [36].

Educational level seems to be an independent predictor of portal usage: in an inpatient study, after adjustment for age, gender, race/ethnicity, immigration status, educational attainment, and employment status, those without an education degree had higher odds of never logging on to the portal [20]. Previous studies also found that patients with higher eHealth literacy levels have a higher likelihood of being a portal user [32-31]. Similar findings were reported by Holt KA et al (2019), suggesting that information about patients' health literacy may provide a better understanding of patients' reasons for not using digital health services, rather than sociodemographic data [37].

The association between having a good overall health status and a lower likelihood of being a portal user was also documented in previous studies. People with disabilities and chronic conditions, frequent users of healthcare services (as well as caregivers of elderly parents or children) tend to be associated with higher patient portal interest and usage [19, 22]. In this study, we did not find any significant associations with age, gender, ethnicity or geographic location. The association between age and portal usage has been inconsistently reported: while some studies have suggested that elderly persons use portals less often [19,22,23], others did not find a significant effect [38]. Mixed results have also been found regarding gender differences [39-40]. It has been previously suggested that ethnic minorities use patient portals less often [41]. However, a study evaluating disparities in enrolment and use of a patient portal concluded that while minority patients were less likely to register to use a patient portal, there were no racial/ethnic disparities in use of the patient portal among enrollees, suggesting the digital divide may be particularly important at enrolment, rather than in continued usage (i.e., post-enrolment) [42]. It is likely that the association between ethnicity and portal usage results from a complex relationship modelled by a range of sociodemographic, economic and educational variables. In the present study ethnicity was not, per se, an independent predictor of portal usage.

A significant association was found between portal use and patient activation (expressed as the subjective motivation to be involved in one's own care), but significance did not remain in multivariate analyses - in fact, this variable was removed from the best fit model as part of the stepwise backwards procedure. A few studies exploring this aspect have found inconsistent results: while one study found slightly higher Patient Activation Measure (PAM) scores in portal users [43], others found no significant associations between PAM levels and portal log-in [44].

## Strengths and limitations

This study has several strengths. The size of the sample is 75% higher than the estimated minimum sample size to ensure representativeness and adequate statistical power. A comprehensive set of characteristics were collected and analysed, at individual level, allowing us to explore not only the classic demographic factors (age, gender, ethnicity, educational level), but also important variables such as overall health status, motivation to self-manage, and health literacy (using a validated tool). The high response rate, and the overall large sample size, contribute to the robustness of these findings.

Some limitations should also be acknowledged. First, it must be noted that, although we achieved the minimum sample size required, the overall response rate was low, which has important considerations for generalisations about which determinants drive portal adoption. Intrinsically to the study design, a range of selection biases cannot be excluded. Although online surveys are a well-accepted method for data collection, it induces a selection bias by excluding individuals with less digital literacy, less tech-savvy, with less consistent access to the internet, and therefore those who are less likely to adopt patient portals. Using an exclusively online recruitment strategy also introduces an additional selection bias, but unfortunately, we weren't able to email participants directly due to information governance limitations. Additionally, both users and non-users are registered at the portal, and therefore our results highlight potential determinants of use amongst registered users, and not general determinants of initial engagement with the portal. This needs to be taken in account in any attempt to perform external generalisations. While this study aims to identify the determinants of usage between those that had already registered (not the determinants to engage / register with a portal in a first instance), future research should also address which are the determinants for initial engagement (i.e., register with a portal in a first instance).

In this study, patient portal usage was patient-reported, and therefore a potential information bias can also be present. As an alternative, patient log-in can be used to measure portal use,<sup>40</sup> however this approach lacks contextual information.

It is also important to note that most subjects included in this study are predominantly from a specific geographic location (North West London), and therefore these results need to be carefully interpreted in any attempt to perform external generalisations (i.e. to other geographic locations, populations, or healthcare systems). As future work, it would be important to evaluate not only the geographic location of the users, but also whether users live in an urban, rural or mixed setting, given the variation in accessibility (i.e., internet access, connectivity options) between those.

Finally, the aim of this study was to evaluate the impact of individual factors, but there is a plethora of socio-technical factors (including, for example, social determinants, portal design, and communication strategies) that may equally influence adoption rates and which impact is important to evaluate in future research.

## Conclusions

This work adds to the growing body of evidence highlighting the importance of educational aspects (educational level and digital literacy) for sustainable implementation and use of patient-facing electronic health record portals. To ensure that all patients are able to benefit from patient portals, it is critical that we move from identifying disparities in portal usage to systematically addressing them through patient-centred interventions that reduce a digital divide.

Further research evaluating the impact of interventions to improve portal usage must therefore explore the effect on potential disparities in use, addressing the impact on patients with a low educational level, poor access to technology, or lack of ability or confidence to use it for health-related purposes.

Equally, portal use can be improved by co-designing portals with patients, incorporating user-centred design techniques, and ensuring that a diverse group of potential users is included in the process. In particular, involving older persons and those with lower general health literacy and digital health literacy in digital development can provide important insights on the barriers experienced by these typically excluded groups, and co-design strategies to overcome them [45].

It is therefore critical to ensure that healthcare providers and policymakers align across sectors, investing and delivering strategic programs that improve access to technology and digital literacy, in an effort to improve digital inclusion and reduce inequities in delivery of care.

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## Conflicts of Interest

None declared.

## Abbreviations

BAME: Black, Asian, and ethnic minorities

BRC: Biomedical Research Centre

CI: Confidence interval

CIE: Care Information Exchange

eHEALS: eHealth Literacy Scale

EHR: Electronic Health Records



ePHR: Electronic Personal Health Record  
NHS - National Health Service  
NIHR: National Institute for Health Research  
OR: Odds ratio  
PKB: Patients Know Best  
SD: Standard deviation



## References

1. Heyworth L, Paquin AM, Clark J, et al. Engaging patients in medication reconciliation via a patient portal following hospital discharge. *J Am Med Inform Assoc* 2014;21(e1):e157-e162.
2. Neves AL, Freise L, Laranjo L, Carter AW, Darzi A, Mayer E. Impact of providing patients access to electronic health records on quality and safety of care: a systematic review and meta-analysis [published online ahead of print, 2020 Jun 12]. *BMJ Qual Saf* 2020; bmjqs-2019-010581. doi:10.1136/bmjqs-2019-010581.
3. Freise L, Neves AL, Flott K, Harrison P, Kelly J, Darzi A, Mayer EK. Assessment of Patients' Ability to Review Electronic Health Record Information to Identify Potential Errors: Cross-sectional Web-Based Survey. *JMIR Form Res*. 2021 Feb 26;5(2):e19074. doi: 10.2196/19074. PMID: 33635277.
4. Dalal AK, Dykes PC, Collins S, et al. A web-based, patient-centered toolkit to engage patients and caregivers in the acute care setting: a preliminary evaluation. *J Am Med Inform Assoc*. 2016;23(1):80-87.
5. Maher M, Kaziunas E, Ackerman M, et al. User-Centered Design Groups to Engage Patients and Caregivers with a Personalized Health Information Technology Tool. *Biol Blood Marrow Transplant*. 2016;22(2):349-358.
6. Lyles CR, Nelson EC, Frampton S, Dykes PC, Cemballi AG, Sarkar U. Using Electronic Health Record Portals to Improve Patient Engagement: Research Priorities and Best Practices. *Ann Intern Med*. 2020 Jun 2;172(11 Suppl):S123-S129. doi: 10.7326/M19-0876. PMID: 32479176; PMCID: PMC7800164.
7. Sun R, Burke LE, Korytkowski MT, Saul MI, Li D, Sereika SM. A longitudinal examination of patient portal use on glycemic control among patients with uncontrolled type 2 diabetes. *Diabetes Res Clin Pract*. 2020 Dec;170:108483. doi: 10.1016/j.diabres.2020.108483. Epub 2020 Oct 7. PMID: 33038473.
8. Osborn CY, Tenforde M, Jain A, Hickner J. The value of personal health records for chronic disease management: what do we know? *Fam Med*. 2011;43(5):351-354.
9. Kruse CS, Argueta DA, Lopez L, Nair A. Patient and provider attitudes toward the use of patient portals for the management of chronic disease: a systematic review. *J Med Internet Res*. 2015;17(2):e40.
10. Schnipper JL, Gandhi TK, Wald JS, et al. Effects of an online personal health record on medication accuracy and safety: a cluster-randomized trial. *J Am Med Inform Assoc* 2012;19(5):728-734.
11. Chrischilles EA, Hourcade JP, Doucette W, et al. Personal health records: a randomized trial of effects on elder medication safety. *J Am Med Inform Assoc*. 2014;21(4):679-686.
12. Sarkar U, Lyles CR, Parker MM, et al. Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system [published correction appears in *Med Care* 2014 May;52(5):453]. *Med Care* 2014;52(3):194-201.
13. Osborn CY, Mayberry LS, Mulvaney SA, Hess R. Patient web portals to improve diabetes outcomes: a systematic review. *Curr Diab Rep*. 2010;10(6):422-435.
14. Graetz I, Gordon N, Fung V, Hamity C, Reed ME. The Digital Divide and Patient Portals: Internet Access Explained Differences in Patient Portal Use for Secure Messaging by Age, Race, and Income. *Med Care* 2016;54(8):772-779.
15. Archer N, Fevrier-Thomas U, Lokker C, McKibbin KA, Straus SE. Personal health

records: a scoping review. *J Am Med Inform Assoc* 2011;18(4):515-522.

16. Greenhalgh T, Morris L, Wyatt JC, Thomas G, Gunning K. Introducing a nationally shared electronic patient record: case study comparison of Scotland, England, Wales and Northern Ireland. *Int J Med Inform*. 2013;82(5):e125-e138.

17. Fraccaro P, Vigo M, Balatsoukas P, Buchan IE, Peek N, van der Veer SN. Patient Portal Adoption Rates: A Systematic Literature Review and Meta-Analysis. *Stud Health Technol Inform*. 2017;245:79-83. PMID: 29295056.

18. Lober WB, Zierler B, Herbaugh A, et al. Barriers to the use of a personal health record by an elderly population. *AMIA Annu Symp Proc*. 2006; 514-518.

19. Goel MS, Brown TL, Williams A, Hasnain-Wynia R, Thompson JA, Baker DW. Disparities in enrollment and use of an electronic patient portal. *J Gen Intern Med*. 2011;26(10):1112-1116.

20. Sarkar U, Karter AJ, Liu JY, et al. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *J Am Med Inf Assoc* 2011;18(3):318–21.

21. Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. *J Am Med Inform Assoc*. 2011;18 Suppl 1(Suppl 1):i8-i12.

22. Ronda MC, Dijkhorst-Oei LT, Gorter KJ, Beulens JW, Rutten GE. Differences between diabetes patients who are interested or not in the use of a patient Web portal. *Diabetes Technol Ther*. 2013;15(7):556-563.

23. Turner K, Clary A, Hong YR, Alishahi Tabriz A, Shea CM. Patient Portal Barriers and Group Differences: Cross-Sectional National Survey Study. *J Med Internet Res*. 2020 Sep

24. Nagykaldi Z, Aspy CB, Chou A, Mold JW. Impact of a Wellness Portal on the delivery of patient-centered preventive care. *J Am Board Fam Med*. 2012;25(2):158-167.

25. Ancker JS, Osorio SN, Cheriff A, Cole CL, Silver M, Kaushal R. Patient activation and use of an electronic patient portal. *Inform Health Soc Care*. 2015;40(3):254-266.

26. Lazard AJ, Watkins I, Mackert MS, Xie B, Stephens KK, Shalev H. Design simplicity influences patient portal use: the role of aesthetic evaluations for technology acceptance. *J Am Med Inform Assoc* 2016;23(e1):e157-e161.

27. Care Information Exchange – The largest shared patient portal program in the UK. <https://patientsknowbest.com/2019/10/21/care-information-exchange-the-largest-shared-patient-portal-program-in-the-uk/>

28. Office for National Statistics. ONS Postcode Directory 2020. Available from: <http://geoportal.statistics.gov.uk/datasets/ons-postcode-directory-may-2020> [Accessed 13 August 2020].

29. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *J Med Internet Res*. 2006;8(4):e27.

30. Boissunon A, Canu S, Fourdrinier D, Strawderman W, Wells, MT (2014), "Akaike's Information Criterion, Cp and estimators of loss for elliptically symmetric distributions", *International Statistical Review*, 82 (3): 422–439.

31. Davis SE, Osborn CY, Kripalani S, Goggins KM, Jackson GP. Health Literacy, Education Levels, and Patient Portal Usage During Hospitalizations. *AMIA Annu Symp Proc*. 2015; 1871-1880.

32. Irizarry T, DeVito Dabbs A, Curran CR. Patient Portals and Patient Engagement: A State of the Science Review. *J Med Internet Res* 2015;17(6):e148.

33. Davis SE, Osborn CY, Kripalani S, Goggins KM, Jackson GP. Health Literacy, Education Levels, and Patient Portal Usage During Hospitalizations. *AMIA Annu Symp Proc*. 2015;2015:1871-1880.

34. Sanders MR, Winters P, Fortuna RJ, et al. Internet access and patient portal readiness

- among patients in a group of inner-city safety-net practices. *J Ambul Care Manage.* 2013;36(3):251-259.
35. Jung C, Padman R. Virtualized healthcare delivery: understanding users and their usage patterns of online medical consultations. *Int J Med Inform.* 2014;83(12):901-914.
36. Holt KA, Karnoe A, Overgaard D, et al. Differences in the Level of Electronic Health Literacy Between Users and Nonusers of Digital Health Services: An Exploratory Survey of a Group of Medical Outpatients. *Interact J Med Res.* 2019;8(2):e8423.
37. Holt KA, Karnoe A, Overgaard D, et al. Differences in the Level of Electronic Health Literacy Between Users and Nonusers of Digital Health Services: An Exploratory Survey of a Group of Medical Outpatients. *Interact J Med Res.* 2019;8(2):e8423.
38. Woods SS, Forsberg CW, Schwartz EC, Nazi KM, Hibbard JH, Houston TK, Gerrity M. The Association of Patient Factors, Digital Access, and Online Behavior on Sustained Patient Portal Use: A Prospective Cohort of Enrolled Users. *J Med Internet Res* 2017;19(10):e345.
39. Sanders MR, Winters P, Fortuna RJ, et al. Internet access and patient portal readiness among patients in a group of inner-city safety-net practices. *J Ambul Care Manage.* 2013;36(3):251-259.
40. Jung C, Padman R. Virtualized healthcare delivery: understanding users and their usage patterns of online medical consultations. *Int J Med Inform.* 2014;83(12):901-914.
41. Smith SG, O'Connor R, Aitken W, Curtis LM, Wolf MS, Goel MS. Disparities in registration and use of an online patient portal among older adults: findings from the LitCog cohort. *J Am Med Inform Assoc.* 2015;22(4):888-895.
42. Goel MS, Brown TL, Williams A, Cooper AJ, Hasnain-Wynia R, Baker DW. Patient reported barriers to enrolling in a patient portal. *J Am Med Inform Assoc.* 2011;18 Suppl 1(Suppl 1):i8-i12. doi:10.1136/amiajnl-2011-000473.
43. Nagykaldi Z, Aspy CB, Chou A, Mold JW. Impact of a Wellness Portal on the delivery of patient-centered preventive care. *J Am Board Fam Med.* 2012;25(2):158-167.
44. Ancker JS, Osorio SN, Cheriff A, Cole CL, Silver M, Kaushal R. Patient activation and use of an electronic patient portal. *Inform Health Soc Care.* 2015;40(3):254-266.
45. Neves AL, Lawrence-Jones A, Naar L, Greenfield G, Sanderson F, Hyde T, Wingfield D, Cassidy I, Mayer E. Multidisciplinary teams must work together to co-develop inclusive digital primary care for older people. *Br J Gen Pract.* 2020 Nov 26;70(701):582. doi: 10.3399/bjgp20X713645. PMID: 33243904; PMCID: PMC770703

## Supplementary Files

## Figures

Geographic location overview. General overview of England (left) and Central London (right, representing 64.7% of the subjects). Circle size represents the total number of respondents per post code area, and colour code represents the percentage of CIE users per post code area. The right-side image shows the stronger representation of North / West London in the sample.

