BMJ Open Engagement with healthcare providers and healthcare system navigation among Australians with chronic conditions: a descriptive survey study

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ABSTRACT

Objectives With the rate of chronic conditions increasing globally, it is important to understand whether people with chronic conditions have the capacity to find the right care and to effectively engage with healthcare providers to optimise health outcomes.

We aimed to examine associations between care navigation, engagement with health providers and having a chronic health condition among Australian adults.

Design and Setting This is a cross-sectional, 39-item online survey including the navigation and engagement subscales of the Health Literacy Questionnaire, completed in December 2018, in Australia. Binary variables (low/high health literacy) were created for each item and navigation and engagement subscale scores. Logistic regression analyses (estimating ORs) determined the associations between having a chronic condition and the navigation and engagement scores, while controlling for age, gender, level of education and income.

Participants 1024 Australians aged 18–88 years (mean=46.6 years; 51% female) recruited from the general population.

Results Over half (n=605, 59.0%) of the respondents had a chronic condition, mostly back pain, mental disorders, arthritis and asthma. A greater proportion of respondents with chronic conditions had difficulty ensuring that healthcare providers understood their problems (32.2% vs 23.8%, p=0.003), having good discussions with their doctors (29.1% vs 23.5%, p=0.05), discussing things with healthcare providers until they understand all they needed (30.5% vs 24.5%, p=0.04), accessing needed healthcare providers (35.7% vs 29.7%, p=0.05), finding the right place to get healthcare services (36.3% vs 29.2%, p=0.02) and services they were entitled to (48.3% vs 40.6%, p=0.02), and working out what is the best healthcare for themselves (34.2% vs 27.7%, p=0.03). Participants with chronic conditions were 1.5 times more likely to have low scores on the engagement (adjusted OR=1.48, p=0.03, 95% CI 1.05 to 2.08) and navigation (adjusted OR=1.43, p=0.026, 95% CI 1.043 to 1.970) subscales after adjusting for age, gender, income and education. Conclusion Upskilling in engagement and communication

for healthcare providers and people with chronic conditions is needed. Codesigned, clearly articulated and accessible information about service entitlements

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A broadly representative sample of adult Australians were recruited from the general population.
- ⇒ Validated navigation and engagement subscales from the Health Literacy Questionnaire (HLQ) were used to assess care navigation and engagement with healthcare providers.
- ⇒ Collection of demographics, including age, gender, educational level, socioeconomic status and presence or absence of chronic conditions, enabled multivariate analysis of associations with navigation and engagement.
- \Rightarrow Limited participation of younger age groups (<25 years) limits the generalisability of our results to these populations and surveys of larger samples are planned.
- ⇒ Using only the navigation and engagement scales on the HLQ limits our understanding of the potential associations among the nine domains of the HLQ to provide a more holistic measure of HLQ.

and pathways through care should be made available to people with chronic conditions. Greater integration across health services, accessible shared health records and access to care coordinators may improve navigation and engagement.

BACKGROUND

The focus of healthcare delivery has changed in recent decades. Instead of delivering care *to* people ('paternalistic care'), the system now aims to deliver care *with* people to meet their individual needs and preferences ('person-centred care'). This shift recognises that person-centred care improves service quality and appropriateness while supporting capacity for self-care and reducing the burden on healthcare services.¹² Person-centred care involves the active participation of healthcare consumers in their care through two-way communication and shared decision-making

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Table 1 Demo	graphic and health charact	eristics
Characteristics	n* (%)†	
Overall		1024
Gender	Male	502 (49.0)
	Female	522 (51.0)
Age (years)	18–24	123 (12.0)
	25–44	379 (37.0)
	45–64	328 (32.0)
	65+	195 (19.0)
State	Australian Capital Territory	20 (2.0)
	New South Wales	328 (32.0)
	Northern Territory	10 (1.0)
	Queensland	205 (20.0)
	South Australia	72 (7.0)
	Tasmania	20 (2.0)
	Victoria	266 (26.0)
	Western Australia	102 (10.0)
Rurality	Metropolitan	588 (57.4)
	Regional/remote	436 (42.6)
Education	Less than year 12	125 (12.3)
	Year 12 or equivalent	167 (16.3)
	Technical/trade	369 (36.1)
	Bachelor's degree	248 (24.3)
	Postgraduate degree or higher	113 (11.1)
Weekly household income	<\$A1500	702 (68.5)
	≥\$A1500	322 (31.5)
Chronic condition	None	419 (41.0)
	≥1	605 (59.0)
*I Inwoighted num		

*Unweighted number.

†Percentage weighted for age, sex and state; columns may not equal total N due to missing demographic responses.

with healthcare professionals where trust and respect are central supporting values.³

Adequate health literacy is an important determinant in the success of person-centred care⁴⁻⁶ and is important for optimising health outcomes. Health literacy is the person's ability to access, understand and act on health information. People who have high health literacy are more likely to understand their own healthcare needs, take appropriate action in response to these needs, participate in decision-making about their care, are able to self-care and navigate healthcare services to access appropriate care as needed.⁷⁸

Despite the known benefits of high health literacy, approximately 60% of Australian adults are estimated to have low health literacy.⁹ Australia is not unique in this respect; more than 50% of the adult population in 12 countries of the Organisation for Economic Co-operation and Development (eg, The Netherlands, Spain, Japan, Czech Republic and Germany) report low health literacy.⁴ Socioeconomic gradients and inequalities have been shown to correlate with levels of health literacy. People living with socioeconomic disadvantage, those with low educational attainment and those with lower income have been consistently reported to have lower health literacy in Australia and globally.^{9–11}

Managing multiple medications, care providers and services, as is often the case for people with chronic conditions, further demands high health literacy to support capacity for self-care, navigate complex and often siloed care services, and communicate effectively with many different types of care providers.^{12 13} International studies have suggested that health literacy in people with chronic conditions may be higher than those without chronic conditions due to system exposure and experience,¹⁴ while other studies report lower health literacy as people with chronic conditions report limited capacity to self-manage and navigate complex care systems, negatively impacting their health outcomes.^{15 16} However, there is limited evidence on health literacy levels among people living with chronic conditions in the general Australian population. Furthermore, there is limited information about specific health literacy domains that are essential for the health of this population, that is, their ability to actively engage with healthcare providers and their ability to navigate the healthcare system. The concept of engagement includes the ability to converse with healthcare professionals to ensure their needs are understood, that they understand healthcare instructions, for example when taking medications, and that they feel confident to seek help from a health professional when needed. Health navigation refers to the ability of patients to identify needed entry points to health services and health prevention programmes so that they access the care they need when they need it. The relationship between health literacy and chronic disease has mainly been studied in the context of disease prevention or disease management for specific chronic diseases, with limited data available about the ability of people living with chronic disease in the general population to engage with healthcare professionals or to navigate and access health services.¹⁷

In this study, we aimed to identify differences in two domains of health literacy, engagement and navigation, between Australians living with chronic conditions compared with those who have no chronic conditions. We hypothesised that levels of engagement and navigation would be significantly lower in adults with a chronic condition than adults without a chronic condition.

METHODS

Participant recruitment and procedure

Australian adults aged ≥18 years were recruited to take part in an online survey between 29 November and 14 December 2018 through a market research company ResearchNow (since rebranded as Dynata; https://www.

Table 2	Proportion of respondents indicating difficulty in the engagement and navigation subscales of the Health Literacy
Question	nnaire (N=1024)

Difficult*, n (%)
295 (28.8)
292 (28.5)
274 (26.8)
287 (28.0)
251 (24.5)
314 (30.7)
341 (33.3)
319 (31.2)
342 (33.4)
462 (45.1)
323 (31.5)

*Score ≤3 indicates difficulty (cannot do or always difficult, usually difficult, or sometimes difficult).

dynata.com/), which operates several national and international panels with over 11 million panellists worldwide and with more than 200 000 panellists registered in Australia.

ResearchNow was contracted to source participants based on representative quotas for age, gender and geographical location. Potential participants were invited to take part via email. Informed consent was provided through the opt-in process and the action of choosing to participate in the survey. While no monetary incentive was offered by the researchers, participants were paid a small fee (\$A1.50) by ResearchNow for completing the online survey.

Survey design

A 39-item online survey was codesigned with consumerresearchers from the Consumers Health Forum of Australia and academic researchers from the National Health and Medical Research Council Partnership Centre for Health System Sustainability. Details of the survey are reported in detail elsewhere.^{18 19} Information about participants' gender, age, postcode, level of education and household income was collected. Drawing on the Australian Bureau of Statistics (ABS) National Health Surveys,^{20 21} the questionnaire included items on financial stress,²² access to healthcare including barriers to access, use of health services, and the opinions and experiences of Australians while accessing the healthcare system.^{23–25} In this study, we focus specifically on engagement with healthcare providers and navigation of the health system. The survey questions relevant to this study are detailed in online supplemental additional file 1.

Health literacy

Two sub-scales from the Health Literacy Questionnaire (HLQ) were used: 'Ability to actively engage with healthcare providers' (engagement: five items) and 'Navigating the healthcare system' (navigation: six items).²⁴ Items were rated on a 5-point Likert scale ranging from 'cannot or always difficult' to 'always easy'.²⁶ The average scores for each scale were calculated using all the items from that scale according to published scoring rules.²⁷ Lower scores indicate greater difficulties in engagement and navigation. Both scales of the HLQ have been validated and show excellent internal consistency (Cronbach's α >0.80).^{26 28} In the present study, there was high internal consistency, with Cronbach's α coefficients of α =0.95 for engagement and α =0.94 for navigation.

Chronic conditions and demographics

Respondents were asked to select whether they had any of the following long-term chronic health conditions: arthritis, asthma, back pain or back problems, cancers, cardiovascular disease, chronic obstructive pulmonary disease, diabetes or mental disorders, based on the Australian Institute of Health and Welfare's (AIHW) major groupings and definitions of chronic conditions in 2018.²⁰ Participants without chronic conditions chose 'I do not have any of the chronic illnesses listed'.

Data transformation and analysis

Although we sought to recruit a representative Australian sample, the data were not entirely representative and therefore we postweighted the data by age, gender and state to reflect population distribution according to the ABS in June 2018.²⁹ The survey was postweighted through a survey raking technique using the anesrake package in R.³⁰

 Table 3
 Comparisons between groups with and without chronic conditions on single-item scores in the engagement and navigation subscales

	Chronic condition (n=605)	No chronic condition (n=419)	
	Difficult, n (%)	Difficult, n (%)	χ²
Engagement			
E1. Make sure that healthcare providers understand your problems properly.	195 (32.2)	100 (23.8)	8.58*
E2. Feel able to discuss your health concerns with a healthcare provider.	183 (30.2)	109 (25.9)	2.25
E3. Have good discussions about your health with doctors.	176 (29.1)	99 (23.5)	3.85*
E4. Discuss things with healthcare providers until you understand all you need to.	184 (30.5)	103 (24.5)	4.33*
E5. Ask healthcare providers questions to get the health information you need.	158 (26.1)	94 (22.3)	1.87
Navigation			
N1. Find the right healthcare.	198 (32.8)	116 (27.7)	3.02
N2. Get to see the healthcare providers I need to.	216 (35.7)	125 (29.7)	3.94*
N3. Decide which healthcare provider you need to see.	202 (33.4)	117 (28.0)	3.45
N4. Make sure you find the right place to get the healthcare you need.	219 (36.3)	122 (29.2)	5.68*
N5. Find out which healthcare services you are entitled to.	292 (48.3)	170 (40.6)	5.92*
N6. Work out what is the best healthcare for you.	207 (34.2)	116 (27.7)	4.89*

Postcode data were mapped to the Australian Statistical Geography Standard, which has five categories: 'metropolitan', 'inner regional', 'outer regional', 'remote' and 'very remote'.³¹ Due to limitations in sample size, the five categories were collapsed into two ('metropolitan' and 'regional/remote'). To assess weekly household income (after tax), participants selected one of four categories (online supplemental additional file 1). For analysis, we collapsed income into two categories: those with weekly income <\$A1500 and those with income \geq \$A1500, approximating results from the ABS Survey of Income and Housing,³² which reported a median household income of \$A1701 in 2018.³² Respondents who reported one or more of the eight chronic health conditions were classified as having a chronic condition.

The individual health literacy items and the two scale scores were analysed using descriptive statistics. A binary variable was created for each item and respective scale to determine those in a lower health literacy group because it offers more meaningful results. Guided by previous research,³³ 'lower health literacy' was deemed as a score of ≤ 3 for each item and scale because scores of 1–3 on each item indicate a level of difficulty ('cannot do or always difficult', 'usually difficult' or 'sometimes difficult'), while scores of 4 and 5 indicate high health literacy or 'easy' ('always easy' or 'usually easy'). A percentage of respondents scoring in the 'difficult' range were also computed for each item. χ^2 analyses were used to determine whether there were significant differences in binary item scores

between respondents with and without chronic conditions. Finally, two logistic regression models were tested using binary ('difficult'=0 or 'easy'=1) engagement and navigation scale scores as dependent variables in each model, respectively. Several variables were recoded for ease of analysis and interpretation. Independent demographic predictor variables, including gender (male=0, female=1), age (45-65+ years=0, 18-44 years=1), rurality (metropolitan=0, rural/remote=1), level of education (university degree or higher=0, less than a university degree=1) and household income per week (\geq \$A1500=0, <\$A1500=1) were entered in step 1, followed by chronic condition (no chronic condition=0, one or more chronic conditions=1) in step 2. Crude and adjusted ORs with 95% CIs were calculated to measure the odds of being in the lower health literacy group compared with higher health literacy, as defined above. Significance was set at p<0.05 for all tests. All statistical analyses were performed using IBM's SPSS Statistics V.25.34

Patient and public involvement

No patients were involved.

RESULTS

Demographic and health characteristics

The 1024 participants were aged between 18 and 88 years (mean 46.6, SD=17.2), 51.0% of whom were female. Almost half of the respondents reported that their

Variable	COR (95% CI)	AOR (95% CI)
Gender		
Male (ref)	1.00	1.00
Female	0.99 (0.73 to 1.38)	0.85 (0.61 to 1.18)
Age (years)		
45–65+ (ref)	1.00	1.00
18–44	1.93 (1.40 to 2.68)**	2.25 (1.59 to 3.18)**
Region		
Metropolitan (ref)	1.00	1.00
Rural/remote	0.85 (0.61 to 1.17)	0.86 (0.61 to 1.21)
Education		
University degree or higher	1.00	1.00
Less than a university degree	1.19 (0.85 to 1.67)	1.27 (0.88 to 1.82)
Income		
≥\$A1500	1.00	1.00
<\$A1500	1.40 (0.98 to 2.01)*	1.49 (1.02 to 2.17)*
Chronic condition		
None	1.00	1.00
One or more	1.53 (0.98 to 1.84)*	1.48 (1.05 to 2.08)*

The total number of cases included in the analysis was 1021 due to missing data in 3 cases.

Independent predictor variables were coded as the following: gender (male=0, female=1); age (0=45-65+ years, 1=18-44 years); region (0=metropolitan, 1=rural/remote); level of education (university degree or higher=0, less than a university degree=1); income (\geq \$A1500=0, <\$A1500=1); chronic condition (none=0, one or more=1).

*P<0.05, **P<0.001.

AOR, adjusted OR; COR, crude OR; ref, reference.

average weekly household income after tax was between A500 and A1499 (n=491, 47.9%), and 20.6% (n=211) reported their income to be less than A500, which is broadly consistent with ABS data from 2018.³² All participants reported use of a healthcare service in the last 12 months, with visiting a general practitioner (GP) being the most common (n=866, 84.6%). Unweighted and weighted participant demographic and health characteristics are presented in table 1. Almost two-thirds of the respondents had one or more chronic condition(s) (n=605, 59.0%), including back pain/problems (n=260, 25.4%), mental disorders (n=244, 23.8%), arthritis (n=172, 16.8%) and asthma (n=135, 13.2%).

Health literacy profile of the whole sample

Out of a maximum score of 5, the mean score for the HLQ engagement scale was 3.85 (SD=0.79) and for the navigation scale 3.70 (SD=0.76). Over 30% of respondents reported difficulties with all items on the navigation scale, with 45.1% indicating difficulties finding out to which healthcare services they were entitled (table 2).

Health literacy profiles of those with and without a chronic condition

Across all engagement and navigation items, the mean scores for participants with a chronic condition were lower, indicating lower health literacy, than those without a chronic condition, although the differences were not always significant (table 3). A significantly higher proportion of participants with a chronic condition reported having more difficulty with engagement, including making sure that healthcare providers understood their problems properly (E1), having good discussions about their health with doctors (E3) and discussing things with healthcare providers until they understand all they need to (E4) (table 3). A significantly higher proportion of respondents with chronic conditions also had difficulty with getting to see the healthcare providers they needed to (N2), making sure they find the right place to get the healthcare they needed (N4), finding out which healthcare services they are entitled to (N5) and working out what is the best healthcare for them (N6) (table 3).

Predictors of difficulties with engagement and navigation

For engagement, results from adjusted logistic regression models identified that participants with a chronic condition were 1.48 times more likely to report difficulties with engagement (OR=1.48, p=0.03, 95% CI 1.05 to 2.08) (table 4). Younger participants aged 18–44 years (OR=2.25, 95% CI 1.59 to 3.18) and participants with a weekly household income <\$A1500 (OR=1.49, 95% CI 1.02 to 2.17) were also more likely to report difficulties with engagement (table 4).

		021)
Variable	COR (95% CI)	AOR (95% CI)
Gender		
Male (ref)	1.00	1.00
Female	0.96 (0.71 to 1.29)	0.81 (0.60 to 1.10)
Age (years)		
45–65+ (ref)	1.00	1.00
18–44	1.82 (1.35 to 2.46)**	2.16 (1.57 to 2.98)**
Region		
Metropolitan (ref)	1.00	1.00
Rural/remote	0.89 (0.66 to 1.21)	0.89 (0.65 to 1.23)
Education		
University degree or higher	1.00	1.00
Less than a university degree	1.29 (0.94 to 1.77)	1.35 (0.96 to 1.89)
Income		
≥\$A1500	1.00	1.00
<\$A1500	1.46 (1.05 to 2.05)*	1.54 (1.09 to 2.20)*
Chronic condition		
None	1.00	1.00
One or more	1.51 (0.97 to 1.78)*	1.43 (1.04 to 1.97)*

The total number of cases included in the analysis was 1021 due to missing data in 3 cases.

Independent predictor variables were coded as the following: gender (male=0, female=1); age (0=45-65+ years, 1=18-44 years); region (0=metropolitan, 1=rural/remote); level of education (university degree or higher=0, less than a university degree=1); income (\geq \$A1500=0, <\$A1500=1); chronic condition (none=0, one or more=1).

*P<0.05, **P<0.001.

AOR, adjusted OR; COR, crude OR; ref, reference.

Similarly, in the second model, results from adjusted logistic regression models identified that participants with a chronic condition were 1.43 times more likely to report difficulties with navigation (OR=1.43, 95% CI 1.043 to 1.970) (table 5). Younger participants (OR=2.16, 95% CI 1.57 to 2.98) and participants with a weekly house-hold income <\$A1500 (OR=1.54, 95% CI 1.09 to 2.20) were also more likely to report difficulties with navigation (table 5).

DISCUSSION

This study suggests that having a chronic condition is an independent factor associated with low health literacy, in terms of engagement with health professionals and navigation of the health system, outside of other previously studied risk factors such as age,^{35–37} cultural and linguistic diversity,^{37 38} and low educational attainment or social disadvantage.^{11 37–39} Our findings are broadly consistent with other Australian and international literature^{14 16 39 40}; however, few studies have focused specifically on difficulties with engagement and navigation as experienced in cohorts recruited from the general population.

An individual's ability to engage with and navigate healthcare is not only influenced by sociodemographic factors as described above, but also by local contexts, including availability, accessibility and suitability of health services. For example, complex health system structures and fragmentation,⁴¹ including complex reimbursement mechanisms, relatively siloed primary, secondary and tertiary health sectors, varied and changeable inclusions covered by private health insurance, lack of clear information on reimbursements and entitlements, and little built-in sign-posting to nudge consumers towards available services,⁴² are likely to contribute to difficulties in care navigation for people with chronic conditions, who often need large healthcare teams.^{42 43} The known inequitable geographical distribution of health services⁴⁴ and appropriateness of health services to meet the needs of diverse and disadvantaged populations¹¹ may further compound difficulties in engagement and navigation. Additionally, opportunities for true person-centred engagement for people with chronic conditions may also be limited due to stagnant GP consultation times (~15 min per consultation) over the last decade⁴⁵ despite increasing presentations of patients with increasingly complex chronic conditions and multimorbidity.⁴⁶ The current healthcare system structure and delivery models in Australia may not be fit-for-purpose to support person-centred care delivery and shared decision-making opportunities for people with chronic conditions. Strong advocacy by healthcare consumer groups,⁴⁷ healthcare professionals' groups and through national policy^{48–50} holds promise; however, a greater focus on change implementation at the coalface of care is needed to realise the benefits of person-centred care and engagement.

Our results suggest that healthcare providers cannot assume that individuals who have a chronic condition know how to appropriately engage with or navigate the healthcare system. System-based solutions are needed to support health consumers to better navigate and engage with the healthcare system, including development and implementation of integrated care practices and models of care, such as the involvement of care navigators who work with patients, healthcare professionals and services to smooth care pathways.⁵¹ Local solutions can include appropriate and accessible health information for consumers, and implementation of motivational interviewing techniques, using clear, short instructions and teach-back techniques by healthcare professionals. However, the evidence for the wide adoption and effectiveness of such techniques is limited.¹⁶ Chronic disease self-management programmes have shown the potential for improvement in health literacy across all domains, including engagement and navigation.⁵² Further robust research is required to scope context-appropriate and patient-centred solutions to improve health literacy,⁵³ and to support people living with chronic health conditions to engage with and navigate health systems with greater ease.

In addition to chronic conditions, we also identified that younger people and those with lower income had low health literacy on the two subscales of HLQ. Our finding regarding income is concordant with previous research that has consistently identified that educational attainment and lower income are associated with low health literacy. $^{10\,53\,54}$ Although previous research has suggested that older age is associated with overall lower health literacy,^{10 55 56} other studies examining health literacy at a subscale level have identified, like us, that older people have fewer difficulties in engaging with healthcare providers than younger people (aged 25-45 years).⁵⁷ Our results align with a large Danish study that reported greater capabilities of older people (45+ years) to engage with healthcare providers.⁵⁶ Older people have greater personal experience of accessing the healthcare system for themselves or their families and have therefore developed greater confidence about engaging with healthcare professionals and greater knowledge about navigating and accessing needed healthcare services, through experience. These results underscore the importance of treating health literacy as a 'multidimensional concept', with the need for future research to examine the impact of age across the other seven HLQ⁵⁶ health literacy domains.

As in many surveys, our study is limited by the sample size and under-representation of younger people. Nevertheless, we applied a postweighting adjustment to our data set to address this issue. Future surveys will aim to recruit larger samples with oversampling techniques to ensure adequate number of people aged under 30 years. In our survey, participants self-reported the presence or absence of chronic conditions, and we had a slight overrepresentation of people with chronic conditions in our sample (59.0%) when compared with estimates from the AIHW $(50\%^{58})$. However, self-reporting is considered an acceptable method of capturing chronic condition prevalence,⁵⁹ and people with health concerns are more likely to respond to surveys such as ours. Owing to inadequate sample sizes for certain condition types and combinations of multiple conditions, we were unable to examine by number of conditions and at an individual condition level, although this is an area for future research. Our survey was further limited because we used only two HLQ subscales, rather than the entire tool, which limited our ability to understand potential associations among the nine domains covered in the HLQ.²⁸ However, we were particularly interested in the engagement and navigation of health systems as experienced by people with chronic conditions, while ensuring brevity of the broader survey.^{18 19}

CONCLUSION

Our survey demonstrated that having a chronic condition was an independent predictor of difficulties with engagement and navigation, in addition to other previously studied predictors of health literacy, such as age, income and gender. Evidence-based solutions for increasing health literacy among populations are currently limited and need to be scoped, trialled and implemented to ease engagement and navigation and to smooth patient journeys, especially for people living with chronic conditions.

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Open access

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8

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