

# Health literacy of patients attending cardiac rehabilitation

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# Health literacy

- The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information for good health
- A strong predictor of health outcomes and behaviours
- Low health literacy is common in the Australian population and associated with low income and educational attainment, as well as with higher risk behaviours
- Little is known about the health literacy of CR attendees compared to those who dropout from programs, or about the impact of CR programs upon health literacy

# Aims

- To describe the health literacy profiles of cardiac rehabilitation attendees and those who drop out from a program.
- Identify whether a CR program, as currently delivered, leads to improved health literacy among attendees.

# Methods

- Between July 2015 and Oct 2016, health literacy and demographic data were collected from patients attending cardiac rehabilitation at Caulfield
- *Eligibility criteria:* Able to provide informed consent. Able to understand one of the following languages: German, Italian, Greek, Vietnamese, Arabic or simplified Chinese
- Data were collected on admission and discharge to the program
- A total of 60 participants completed the baseline data collection, and 38 completed post-program evaluation

**RESEARCH ARTICLE**

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# The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ)

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## Abstract

**Background:** Health literacy has become an increasingly important concept in public health. We sought to develop a comprehensive measure of health literacy capable of diagnosing health literacy needs across individuals and organisations by utilizing perspectives from the general population, patients, practitioners and policymakers.

**Methods:** Using a validity-driven approach we undertook grounded consultations (workshops and interviews) to identify broad conceptually distinct domains. Questionnaire items were developed directly from the consultation data following a strict process aiming to capture the full range of experiences of people currently engaged in healthcare through to people in the general population. Psychometric analyses included confirmatory factor analysis (CFA) and item response theory. Cognitive interviews were used to ensure questions were understood as

RESEARCH ARTICLE

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# Measuring health literacy in community agencies: a Bayesian study of the factor structure and measurement invariance of the health literacy questionnaire (HLQ)

Gerald R. Elsworth\*, Alison Beauchamp and Richard H. Osborne

## Abstract

**Background:** The development of the Health Literacy Questionnaire (HLQ), reported in 2013, attracted widespread international interest. While the original study samples were drawn from clinical and home-based aged-care settings, the HLQ was designed for the full range of healthcare contexts including community-based health promotion and support services. We report a follow-up study of the psychometric properties of the HLQ with respondents from a diverse range of community-based organisations with the principal goal of contributing to the development of a soundly validated evidence base for its use in community health settings.

## Scales:

1. Feeling understood and supported by healthcare providers
2. Having sufficient information to manage my health
3. Actively managing my health
4. Social support for health
5. Appraisal of health information
6. Ability to actively engage with healthcare providers
7. Navigating the healthcare system
8. Ability to find good health information
9. Understand health information well enough to know what to do

## Example Questions:

- I can rely on at least one healthcare provider
- I am sure I have all the information I need to manage my health effectively
- I spend quite a lot of time actively managing my health
- I have at least one person who can come to medical appointments with me
- When I see new information about health, I check up on whether it is true or not
- Discuss things with healthcare providers until you understand all you need to
- Decide which healthcare provider you need to see
- Get health information in words you understand
- Understand what healthcare providers are asking you to do

Survey and interview findings



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**Table 1: Demographic characteristics**

Age in years (mean, standard deviation)	60.3	11.7
Lives alone	13	23.6%
English spoken at home	54	98.2%
Private health insurance	39	68.4%
Secondary education only	13	23.7%
TAFE/ Trade	18	32.7%
Undergraduate or post-graduate	24	43.7%
Full-or part time employment	34	61.8%
Retired	12	21.8%
<i>Self-reported health conditions</i>		
Arthritis or back pain	17	28%
Heart condition	23	38%
Depression or Anxiety	6	10%
No previous health condition	17	28%

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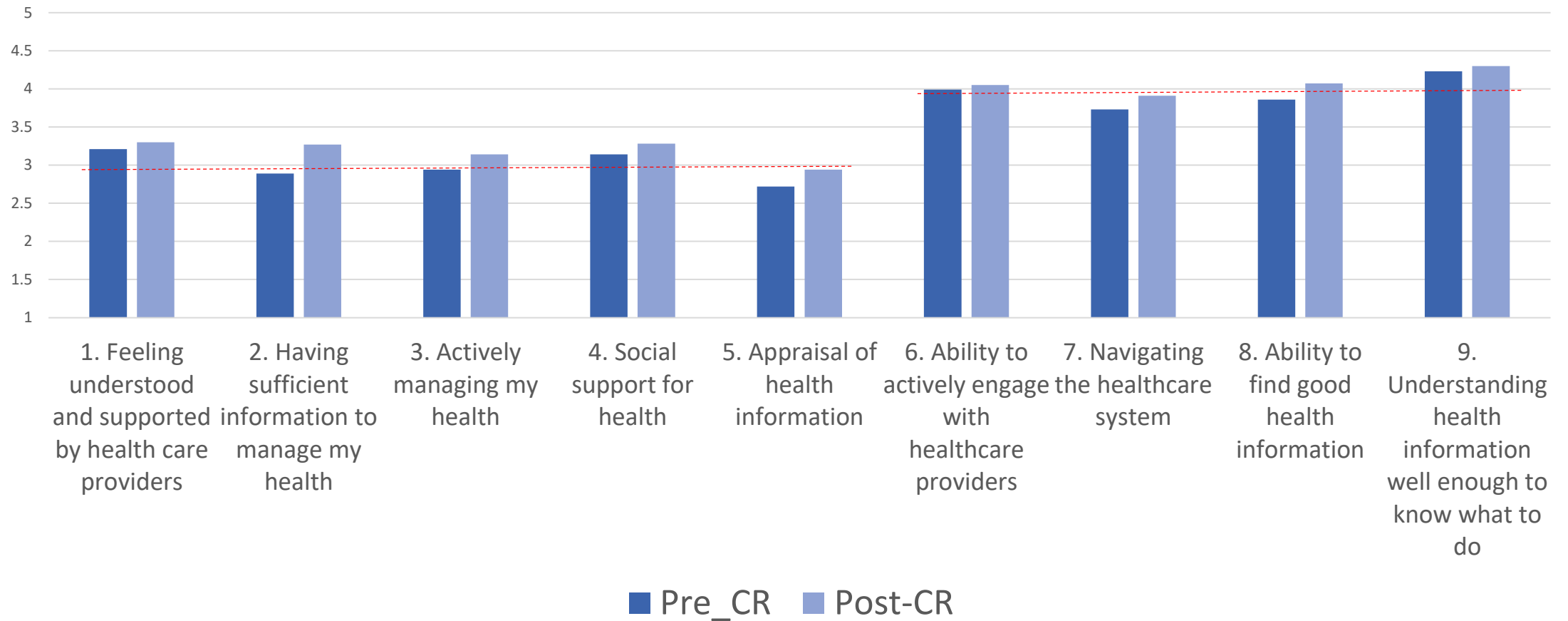
**Table 2: Reason for referral and program attendance (n=60)**

<i>Diagnosis / reason for referral</i>	<i>Number</i>	<i>Percent</i>
Ischaemic heart disease	8	13.3%
Stent only	5	8.3%
Heart failure / cardiomyopathy	8	13.3%
CABG	10	16.7%
AMI +/- Stent	23	38.3%
Other	6	10.0%
<i>CR program information</i>		
Number of sessions attended (mean, SD)	12.4	6.3
Dropout from program	11	18.3%
Attended Emergency Department during CR program (data on n=38)	33	86.8%

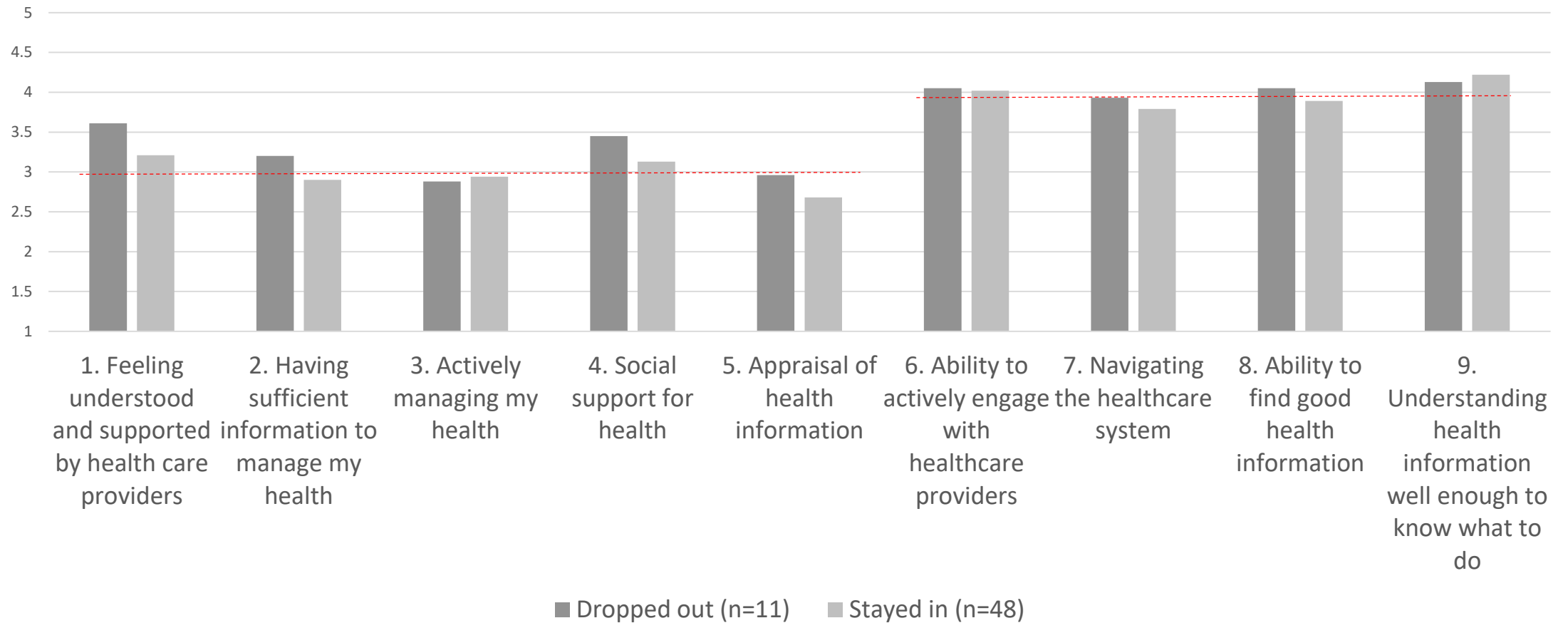
What was the health literacy of the overall sample before starting the CR program, and how did this compare to the general population?

- Health literacy of CR attendees is on average, lower than the general population
- CR attendees scores showed that areas of greatest difficulty were for:
  - *Finding and appraising information*
  - *Feeling that they had enough information*
  - *Navigating the healthcare system*

# Did health literacy change over time?



# How did the health literacy of those who discontinued differ from those who stayed in?



Range of scores for these scales is between 1 and 4. A mean score of <3.00 indicates difficulty.					Range of scores is between 1 and 5. A mean score of <4.00 indicates difficulty.			
1. Healthcare provider support	2. Has sufficient info	3. Actively managing health	4. Social support for health	5. Appraisal of info	6. Active engagement with providers	7. Navigates healthcare system	8. Finding health info	9. Understands health info
3.70	3.50	3.21	3.66	3.18	4.64	4.46	4.53	4.65

Cluster A, n=16 (28%). Confident and know what they want. Work in partnership with medical profession

- **Health literacy:** Overall, quite high health literacy, but do not always actively prioritise their health (**scale 3**), and do not always think about where their health information comes from (**scale 5**). Confident users of the health system and of health information (**scales 6-9**), and generally feel they have good support (**scales 1 & 4**).
- **Demographics:** Average age 60 years, 80% are male, 44% educated at TAFE or trade, 81% currently employed, 75% have health insurance. 80% live with others. 25% AMI/Stent, 25% CABG. One third report no health condition (44% say they have a heart condition). 13% report anxiety/ depression. **Highest dropout rate in overall sample (31% vs. 19% for overall sample).**
- **Interview data:** very good relationships with medical profession, seem to feel that they can communicate on the same level and know what they want. Do what the doctor advises and monitor their own health very closely.

1. Healthcare provider support	2. Has sufficient info	3. Actively managing health	4. Social support for health	5. Appraisal of info	6. Active engagement with providers	7. Navigates healthcare system	8. Finding health info	9. Understands health info
3.61	3.19	2.84	3.40	2.16	4.11	3.85	3.82	4.38

**Cluster B, n=9 (16%). Relies on what the doctor tells them, passive in their own care.**

- **Health literacy:** Feel they have a good relationship with a healthcare provider (may be GP or CR staff) (**scale 1**), and that most of the time they can ask them questions (**scale 6**). Usually able to understand health information (**scale 9**), and feel that they have almost enough information about their health (**scale 2**), but they are not active seekers of information (**scale 8**), particularly from reliable sources (**scale 5**). Also, doesn't try to navigate the health care system (**scale 7**). Ability to plan for what they need to do is low (**scale 3**).
- **Demographics:** Slightly younger than the overall sample (average age 59 years), 76% are male and none live alone. 11% do not speak English at home, 44% have graduate education and 67% are currently working. 56% say they have a heart condition. 33% have HF, 33% AMI +/- stent. ***This cluster had a higher drop rate than the overall sample (22%).***
- **Interview data:** Doesn't seem to have got as much out of rehab as others - perhaps quite passive, relies on GP for information, doesn't look elsewhere.

1. Healthcare provider support	2. Has sufficient info	3. Actively managing health	4. Social support for health	5. Appraisal of info	6. Active engagement with providers	7. Navigates healthcare system	8. Finding health info	9. Understands health info
3.15	2.87	2.80	2.88	2.82	4.09	3.87	3.94	3.98

**Cluster C, n=13 (22%). Limited experience and knowledge. Keen to stay on top of things and likely to do so with good direction.**

- **Health literacy:** Generally feel they have adequate support from at least one healthcare provider (**scale 1**) who they can talk to (**scale 6**). Otherwise they are not very confident in their ability to find use health information and services, or do not have much experience (31% report no previous health condition).
- **Demographics:** Highest proportion of women (31%), average age 63 years. 15% do not speak English at home, 23% live alone. Nearly half have graduate education, and 38% are employed. 23% of this cluster have AMI +/- stent, 23% had stent only. 23% report back pain. **Lower dropout rate than the overall sample (8%).**
- **Interview data:** could have done with more help and guidance at the time of the event, but has since managed to get on top of things, with some help from psychologists. Managing health has now become a priority (for this cluster, Actively managing health went from 2.80 to 3.03). Goes on the internet sometimes but the information is not that relevant.



1. Healthcare provider support	2. Has sufficient info	3. Actively managing health	4. Social support for health	5. Appraisal of info	6. Active engagement with providers	7. Navigates healthcare system	8. Finding health info	9. Understands health info
2.83	2.70	3.28	3.16	2.90	3.26	3.22	3.64	3.98

Cluster D, n=10 (17%). Shocked by diagnosis and becoming a 'patient'. May have had a bad experience, little trust in health providers, may struggle to work collaboratively.

- **Health literacy:** Fairly engaged in managing their own health (**scale 3**), and have adequate social support for health (**scale 4**). Otherwise have little trust or experience with healthcare services or health information. Appear to have little trust or confidence to build relationships with healthcare providers (**scales 1 & 6**). Can sometimes understand health information (**scale 9**) but do not feel they have enough (**scale 2**) or are unsure of where to find good quality, reliable information (**scales 5 & 8**). Unclear about what services are out there and which services are relevant for them (**scale 7**).
- **Demographics:** Relatively young (average age 55 years). 80% male and half live alone. 60% are graduate educated, 40% are employed. Prior to this event, 50% had no health condition, 30% now report they have a heart condition. 10% report depression or anxiety. 90% of the cluster have had AMI +/- stent, 10% have had CABG. ***This cluster has a relatively low dropout rate (10% vs. 19% for overall sample).***
- **Interview data:** The one interviewee from this cluster had had a bad experience in hospital and had very little trust in healthcare providers. Finds them lacking in empathy and not acknowledging the emotional impact. Felt that CR was not tailored to their needs. "6 months down the track....I still have not been able to find support services to suit me. Had previously been very healthy so had little experience of the health system".

1. Healthcare provider support	2. Has sufficient info	3. Actively managing health	4. Social support for health	5. Appraisal of info	6. Active engagement with providers	7. Navigates healthcare system	8. Finding health info	9. Understands health info
2.98	2.28	2.34	2.68	2.28	3.58	3.22	3.22	3.82

Cluster E, n=10 (17%). Many barriers to engaging in their own care such as cost, lack of time, little social support, or limited motivation and confidence. External support appreciated!

- **Health literacy:** Overall lower health literacy. Have some degree of trust and engagement with healthcare providers (**scales 1 & 6**), and can understand a fair proportion of health information (**scale 9**), but struggle to put information into action (**scale 3**). Also feel that they don't have enough information and don't know where to find good, reliable information about what is right for them (**scales 2, 8, 5, & 7**).
- **Demographics:** Slightly older than average sample (average age 65 years). All male, 50% with graduate education, 50% employed. 20% report back pain. 40% CABG, 30% AMI +/- stent. **20% dropped out.**
- **Interview data:** Cost was an issue for seeing specialists. Another felt the GP was always very busy. One person was a procrastinator, always putting things off because life is busy and other things get in the way. This person felt that a 3 monthly check up for someone to tell them to keep on track would be helpful. A third interviewee felt their GP would be the first port of call for information, but that they would Google something if they felt it was appropriate. Participants thoroughly enjoyed rehab.