Title**: Factors affecting engagement in online healthcare patient information: a systematic review of the literature**

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## Abstract

*Background* The online world is rapidly becoming the primary source of healthcare information. There is a pressing need for online healthcare content not only to be accurate but also engaging. Improved engagement of people with online healthcare content has the potential to inform but also to influence behavioural change to make healthier choices. Factors associated with better engagement with online healthcare content have previously not been well considered.

*Objectives*To identify factors which may improve engagement with online healthcare content and develop a framework to be considered when creating such content.

*Search methods* The Pubmed and MEDLINE databases were searched up to January 2020 and manual cross checking of reference lists of relevant articles was performed. No restrictions on the study type were put. Abstracts and titles were reviewed by two authors independently for relevance. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed.

*Results*Our search returned a total of 814 articles, 56 of which met our inclusion criteria. Studies tended to be observational, non-controlled studies, and a few quasi-experimental studies. Overall, there was significant heterogeneity in the types of interventions and outcome assessments making quantitative assessment difficult. Consensus of all authors resulted in seven categories forming the basis of a framework to assess quality of engagement in online healthcare content : 1. Textual information; 2. Discussion groups; 3. Video content; 4. Visuals/ Pictograph; 5. Accessibility; 6. Stage of patient journey; 7. Credibility and completeness of information.

*Conclusions* Healthcare providers should recognise barriers to understanding as well as barrier to adherence with treatment**.** When producing online healthcare patient information, healthcare providers should consider the categories described which may improve engagement with the content being created.

Key words: patient education; online health information; internet; systematic review

## Introduction

In the United Kingdom over half of patients perform an online search relating to their condition prior to seeing a doctor [1] and up to two-thirds use the internet to obtain health related information at some point in their journey [2,3]. The Internet has become an important source of education for patients, who are increasingly expected to, and are motivated to, play an active role in making decisions related to their health [4]. Patient education is defined as "the process by which health professionals and others impart information to patients that will alter their health behaviours or improve their health status”[5]. This may include information that is factual or related to patient experience, depending on the issue being addressed [6,7]. Reports suggest that 70% of patients would like their physicians to recommend a source of online information relating to their condition, but only 4% of patients receive such a recommendation [8].

Online patient healthcare information has several potential benefits including convenient 24-hour access potentially wherever you are, ability to enhance knowledge acquisition [9,10], reduce anxiety [10] and improve the quality of conversations during health-related encounters. However, online content effect on patient empowerment, self-efficacy, and health attitudes has been found to be variable [10]. This may be due to the absence of an evidence-based framework outlining factors that should be considered for improving engagement with online healthcare information.

In this systematic review, we aim to identify and evaluate factors that should be considered when producing engaging and high-quality online healthcare patient information. We also aim to incorporate these findings into a framework that may be useful as a guide to developing online healthcare information.

## Methods

Following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations, we searched the Pubmed and MEDLINE databases to include articles through to January 2020. The MeSH database was used to derive keywords and search term combinations. We used the following search terms in the PubMed search (((“patient education”) AND (“internet” OR “online” or “web”)) AND “content”) AND “English”) AND (“1965” [Date – Publication]: “3000” [Date – Publication]. All retrieved abstracts and titles were reviewed by two independent investigators (EA and LO) for relevance pertaining to engagement with online healthcare content. Manual cross checking of reference lists of identified papers was done to identify any other potentially relevant studies.

Analysis of themes arising from the results was performed using inductive content analysis [67]. This involved reviewing titles and abstracts (author UJ) and freely generating categories relating to ‘factors associated with high quality and engaging online content’. Categories were named using content characteristic words and these were expanded into subcategories. The number of times a category was reported in articles was totalled and a list of categories was created in order of frequency of mentions. All authors reviewed this list to decide which categories would be included in the final list.

## Eligibility criteria

As this is the first systematic review of its kind, no limitation was placed on study type or on surrogate measures of the outcome described.

## Outcomes

All studies relevant to quality of engagement in online healthcare content were included.

## Results

814 articles were identified. Of these, 108 were selected for full text review based on their title and abstract. Full text screening resulted in the final selection of 56 articles from which seven categories were derived.

![A screenshot of a cell phone

Description automatically generated]()

Figure 1. Article selection flowchart (PRISMA)

### Description of studies

Studies were mostly observational and qualitative. Three randomised controlled trials and five systematic reviews were also identified. Categories relating to ‘factors associated with high quality and engaging online content’ were developed according to themes that were found to arise in the studies identified. The categories settled upon are as follows, the number of papers reporting is included in brackets: 1. Textual information (16 papers) ; 2. Discussion boards/ online groups (3 papers); 3. Video content (11 papers); 4. Visual/ pictographs (1 paper); 5. Device accessibility (12 papers); 6. Stage of patient journey (8 papers), and; 7. Credibility and completeness of information (4 papers; Table 1).

Features relating to these categories, associated with improved quality and engagement behaviour have been described below.

### Textual information

Ernest M et al.[13] conducted a study which employed the ‘DISCERN’ tool to evaluate the quality of written information regarding hormone treatment and surgery which was found to be poor [68]. DISCERN is a validated tool developed by an expert pane through a process of panel debate and healthcare information analysis. It is noted to be the ‘first standardised index of quality of consumer health information.’ [68] DISCERN comprises 15 key questions that investigate publication reliability and details of treatment choices, followed by an overall judgement of quality. Each question is answered on a 5-point scale ranging from No to Yes.

Vivenkanatham et al. [19] evaluated textual information on polymyalgia rheumatica. They concluded that for web-based healthcare content to be effective, readability must be accessible to all literacy levels. Similar conclusions on readability were also reached by Maciolek et al. [20] who reported that patient education materials are most effective when simple language that is accessible to a wide patient population is used. A quality assessment study of web-based content on rheumatoid arthritis [21] analysed readability, applicability and accessibility of patient education websites. The mean reading level was found to be 12.1 (SD 2.3) according to the Flesch-Kincaid readability tool. This tool gives a measure of how difficult a passage written in English is to understand through analysing factors such as word length, sentence length, and total syllables. It provides a grade level according to the United States’ educational system ranging from 5th grade to college graduate [69]. The same study [21] reported that 78% of websites assessed were easy to navigate. Importantly, only 33% of websites were assessed to be visual/hearing impairment friendly.

An evaluation of online information on disorders of sex development noted strengths including the tendency of web-pages to present focussed information in chunks and in a logical sequence [13]. A semi-structured interview study of General Practitioners performed by Hjelmager DM et al. [14] revealed that health information technology applications require textual information which is targeted to patients and written with the input of healthcare professionals.

Rofaiel R, et al. [15] assessed the quality of website information about inflammatory bowel disease using the DISCERN score to assess reliability and the relevance of pertinent details. The mean DISCERN score for patient-searched websites was not statistically different to physician recommended websites (3.21 vs 3.62 respectively, p =0.158). Numerous studies [13,14,16–18] identified that readability, as analysed by the Flesch-Kincaid tool, of web-based information exceeded the recommended 6th – 8th reading grade level [70].

# Three studies evaluate the understandability and actionability of online patient information by utilising the validated Patient Education Materials Assessment Tool (PEMAT) [13, 18, 20]. The tool comprises of inventories (one for print and another for audio-visual content) that list desirable and undesirable characteristics of information and produce a numeric value for understandability and actionability (how easy it is to act on given information) respectively. Scoring ranges from 0-100% and a higher score indicates that the text is more understandable or actionable respectively. Online educational content pertaining to disorders of sexual development and tympanostomy tube placement yielded low actionability scores (mean scores: 23% and 44.6% respectively). Interestingly, a study by Maciolek KA et al [20] found that the PEMAT understandability score for academic institution patient educational material exceeded content created by private institutions (P = .02) and content from websites unaffiliated with a Urologist (P = .01).

### Discussion boards/ online groups

Cedars BE et al. report on a study of patients with urethral strictures who participate in online discussions and share experiences to gain emotional support and find answers [22]. Patients participating in these online groups were more often than not satisfied with their postoperative outcomes. These findings are supported by Teaford D et al. [23] who explored the experiences of new mothers using an online post-partum forum. They found that online forums provided a sense of community and a platform for sharing information. They identified 5 themes pertaining to the participants concept of an online community: social support, anonymity, in-groups, drama and entertainment.

However, the findings of a study by Castaneda et al. [24] highlight the importance of exercising caution with online forums. They evaluated the content of peripheral arterial disease electronic Health (eHealth) forums and found that 15.1% of medical advice given on such platforms were inconsistent with guidelines. Further, the study found 10 of 18 posts related to negative personal experiences with healthcare providers.

### Video based

Pedersen MM, et al. [25] found that four subjects who were interviewed after watching a 14 minute educational video on whiplash injuries felt reassured particularly as it aligned with information received at the hospital. Finnegan G et al. [26] reported that visitors of an information hub where videos were embedded in the webpage had spent longer than two minutes on that webpage, indicating that visitors with average reading capability watch and listen to the video whilst browsing the text. and that their YouTube channel with videos explaining the concept of herd immunity was particularly successful, with visitors spending over six minutes on that page.

In the context of managing health conditions, Button et al. [27] found that video-based content was particularly helpful for patients having physiotherapy for knee injuries as they were able to visualise the correct technique. Patient understanding and confidence was found to be improved by this intervention. In a separate study [28] of 80 anaesthetists using video assisted patient education (VaPE) intervention, 96% reported that patients felt they had a better understanding of the information provided through the VaPE intervention and 97.5% of anaesthetists felt that it was a useful form of patient education. However, 46% noted increased anxiety caused by the intervention.

Interestingly, Ferhatoglu et al. [31] found, in their evaluation of the quality of YouTube content on Sleeve Gastrectomy, that patient experience and advertisement videos were significantly more popular than academic videos created by medical professionals according to the Video Power Index. (p<0.001 and p<0.003 respectively). The Video Power Index assesses video performance by comparing it with leaders in its respective industry, measures its impact and effectiveness across all platforms and facilitates strategies to cater for target audiences [78]. Erdem and Sisik [32] reported similar findings and found no significant association between Video Traction (‘likes’, ‘dislikes’ or ‘views’) and usefulness of content (Spearman’s rank correlation r=-0.038, p=0.614; r=-0.003, p=0.972; r=-0.118, p=0.121 respectively). Interestingly, Erdem and Sisik, found no significant correlation in usefulness to video length (r=-0.106, p=0.161) in contradiction to the findings of Biggs et al. [33] who concluded that medical videos categorised as useful had a mean length of 6 minutes and 51 seconds, with the top 10 rated videos having a mean length of 14 minutes and 47 seconds.

Similar to previous findings, a study conducted to assess the quality of YouTube videos on cataract surgery concluded that videos created by medical organisations such as the National Health Service (NHS) were significantly more useful in terms of educating patients about the procedure than videos sourced by independent medical professionals and other sources (p<0.0001) [12]. Bademci et al. [35] similarly concluded that medical topic videos on deep vein thrombosis sourced from medical professionals and hospitals were significantly more useful than videos from other sources (p<0.001).

In a study, evaluating YouTube content on varicose veins [34] it was found that a majority of videos were dominated by the private healthcare sector where the video content presented a distorted view of treatment options consequently leading to a skewed patient perception of therapeutic options available to them. Not only were 32% of these videos found to be poor quality, but videos from private medical companies were significantly more likely to favour minimally invasive surgery over ligation and stripping when compared to other sources. Once again, there was no significant association found between quality of content and viewing frequency.

### Visual/Pictograph

Pictographs are pictorial representations of words or phrases. Christensen C et al. [30] described the value of pictographs in health communication. The study presents the results of building and testing the game ‘Doodle Health’, which is designed to produce pictographs via crowdsourcing. It found that this method of pictograph creation yielded positive feedback from focus groups with regards to usability and comprehension. Analysis of feedback found 62.2% of participants praised the game, with one respondent describing it as ‘engaging and easy to use’. However, they also found that people from diverse cultural backgrounds have different styles of communication which may render visually presented information as ineffective for minority groups. Crowdsourcing pictographs was suggested as a potential solution to this.

### Device Accessibility

A study by Gogovor et al. [36] concluded that next generation of online educational healthcare programs should integrate apps for reasons of 1) accessibility 2) flexibility and 3) security and trustworthiness. Almost all the studies in our review used web-based platforms and required devices that accessed the web, with some studies requiring devices that accessed the video sharing platform, YouTube, specifically.

A study by Lüchtenberg et al. [37] found that only 18% of the 139 health information web sites evaluated achieved a high standard of accessibility for visually impaired users as assessed by the Web Accessibility Initiative guidelines (WAI). The study concluded that online educational healthcare content should at least meet the requirements of priority 1 (level A) and preferably priority 2 (level AA) of the WAI guidelines. Developers can ensure accessibility by, for instance, having text alternatives for all non-text content and using high contrast ratios of text and images 31.

Few studies used smartphones exclusively to deliver information. Describing the benefits of using a smartphone, Bashi et al. [38] noted that smartphone adoption is becoming widespread meaning more people can be reached, however, studies on how applications should deliver information in terms of interface and content is particularly lacking. Noel et al [39] studied the impact of a mobile medical application on plastic surgery patient care. 60 patients answered questionnaires pertaining to the application and the results supported the application’s utility from the patient perspective. The mean score for the application’s ability to answer patient questions was 4.1/5, and 20% of patients were prevented from unnecessarily calling the emergency department. The use of a smartphone also enabled patients to access information from different locations and could allow for real time disease management. Nicholas, et al. [40] performed a systematic review which revealed that of the 11 studies of applications providing patient information, just a third covered core psychoeducational principals. Further, average user ratings were not correlated with either comprehensiveness or adherence to best practice guidelines (r=-0.11, p=0.80 and r=-0.02, p=0.96 respectively).

### Stage of patient journey

A qualitative study by Gogovor et al. [36] using healthcare professionals and patient focus groups found that healthcare professionals suggested stratifying access to information according to ‘stage of advancement’ in terms of their chronic pain management. A qualitative study of ‘Oneself’ [42], a website designed for use by patients with chronic lower back pain, found it to be an effective adjunct to doctor-patient consultations as patients found they were unable to have all of their queries answered in the limited time of a consultation.

At different stages of a patient journey, decision aids, may be used as adjunctive decision-making tools to support patients. Hagerman et al. [43] performed semi structured interviews of 33 physicians in order to identify desirable characteristics of decisional aids. 20 of 33 physicians stated that patients should be educated on the lack of urgency of making a treatment decision. 84.8% of physicians agreed that decisional aids should be provided to patient’s post-consultation when the patient is at home. Further, 36.4% of physicians deemed it ‘very’ or ‘extremely’ important that decisional aids are designed to be used during and after consultations.

Tailoring information delivery to the stage of the patient journey is further supported by the results of Kim et al. [44] who developed a system to organise online disease-specific information according to a situational knowledge base model. The approach categorises information about a specific disease (e.g. thyroid cancer) into sections corresponding to discrete clinical events (e.g. presentation, fine needle aspiration biopsy, diagnosis. 75 patients complete a questionnaire evaluating the website which found mean usability to be 4.6/5, personal relevance of received information 4.7/5 and comprehension of received information 4.8/5.

### Credibility and completeness of information

A study by Jamison et al. [52] found that 86% of apps for pain conditions reported were created with no involvement by healthcare professionals. A comprehensive study by Bae et al. [12], assessing the quality of the content of YouTube videos for cataract surgery patient education, found that there were an abundance of videos simply showing patients undergoing a live procedure. Over 20% of the educational videos were commercial and hence potentially misleading. This may make it challenging to find high-quality, comprehensive educational videos online.

A study by Pithadia et al. [29] used the American Academy of Dermatology Guidelines as a benchmark to evaluate the accuracy of patient information YouTube videos on psoriasis treatments. It concluded that 12% contained high-quality patient education content and majority were not patient-centric. Similarly, Ferhatoglu et al. [31] used the Journal of American Medical Association (JAMAS) benchmark criteria to assess the educational quality of sleeve gastrectomy YouTube videos and found that this score was significantly higher in university affiliated physician videos than other videos (p<0.001).

The HONcode (Health On the Net) presents a set of eight principles designed to set the quality standard for online patient information. [53] (Fig 1). A study by Laversin L et al [71] compared 165 HONcode certified websites to 165 noncertified websites. Only 0.6% of noncertified websites conformed to the principles of the HONcode compared to 89% of the certified sites (p<0.1). As the study followed certified websites 6 months post certification, the effect of HONcode certification shows short term sustainability.

1. *Authoritative: Qualifications of the authors indicated*
2. *Complementarity; information should support the doctor patient relationship*
3. *Privacy: personal data collected by the site kept private*
4. *Attribution: Cite all references*
5. *Justifiability: Back up claims relating to benefits and performance*
6. *Transparency: Accessible presentation, accurate email contact*
7. *Financial Disclosure: Identify funding sources*
8. *Advertising policy: Clearly distinguish advertising from editorial content*

Figure 2 adapted from: [71]

Table 1. Table studies pertaining to engagement with online content. Studies are according to mode of engagement.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Study | Study type | Content | Outcomes pertaining to quality of online healthcare patient content | Main results |
| 1. Textual information | | | | |
| Chedid RA et al. (2018) [11] | Observational Study | Website textual and visuals aids for prenatal health promotion | Comprehensiveness, evidence-based information, accessibility and inclusivity.  Minimum of three referenced prenatal health topics necessary to be classed as evidence-based | Assessment of prenatal health promotion material revealed that 66.4% of federal, 84.6% of provincial/territorial, 80% of public health regional unit-hosted websites and 87.5% of e-classes were evidence based. Only 25% of municipal websites met this standard.  No P values stated. |
| Ernst MM et al. (2019) [13] | Observational study | Disorders of sex development (DSD) web-based information | The Simple Measure of Gobbledygook (SMOG) determined reading level, the Patient Education Materials Assessment Tool (PEMAT) evaluated content for understandability and actionability, and the DISCERN tool assessed treatment decision-making information | Reading level of webpages as determined with SMOG met or exceeded high-school grade level. The mean (Standard Deviation) PEMAT understandability score for Team Pages and Team Links was 68% (6%). On average pages met below 70% of the understandability criteria. The mean (SD) PEMAT actionability score was 23% (20%) The DISCERN tool found that quality of information relating to hormone treatment and to surgery was poor.  No P values stated |
| Hjelmager DM et al. (2019) [14] | Qualitative study | Online information material for patients with low back pain in general practice | Barriers and facilitators for future use of the HIT application for patients with LBP. | 8 one-hour interviews with GPs revealed the following:   * Content for lower back pain should be validated by GPs * From a trustworthy source * Support ongoing treatment plan   No P values stated |
| Rofaiel R et al. (2018) [15] | Observational study | Websites that describe the biologic agents used as treatment options for inflammatory bowel disease | DISCERN model was used to evaluate the quality of the information content. | Mean DISCERN score across all websites was 3.21 out of a 5-point scale. No significant difference was found between patient-searched and physician-recommended websites, with a mean score of 3.21 versus 3.63, respectively (P=0.158). |
| Alfonso AR et al. (2019) [16] | Observational study | American Cleft Palate-Craniofacial Association-Approved Teams' Websites | Content and readability of team websites. | The mean (SD) reading level 10.7 (1.9) exceeded the AMA-recommended sixth grade reading level.  Children's Hospital-affiliated teams (n = 86) yielded significantly higher content scores (14.8 vs 13.5; *P* = .03)  Children’s hospital teams also had better readability as indicated by lower reading grade level (10.5 vs 11.4; *P* = .04). |
| Ayyaswami V et al. (2019) [17] | Observational study | Online Cardiovascular Disease-Related Health Education Articles | Readability according to 10 readability measures (Flesch Reading Ease, Coleman-Liau Index, Flesch-Kincaid Grade Level, Gunning Fog Index, FORCAST Readability Formula, New Dale-Chall formula, New Fog Count, Simple Measure of Gobbledygook Index, Fry Readability Formula, and Raygor Readability Estimate | All measures that assessed mean reading grade level found that 196 articles were written at a mean (SD) 10.9 (1.8) grade reading level.  99.5% of the articles were written beyond the 5th- to 6th-grade level  No P values stated |
| Fajardo MA et al. (2019) [18] | Systematic review | Online deprescribing patient education materials | Patient Education Material Assessment Tool and the International Patient Decision Aids Standards Inventory.  Readability using Gunning-Fog Index and Flesch-Kincaid Grade level. | PEMs addressing deprescribing of medications for symptom control (81%) were most common.  37% of deprescribing PEMs present potential benefits and harms of deprescribing.  Most PEMs are pitched above average reading levels (average minimum reading level of Grade 12).  No P values stated |
| Vivekanantham A et al. (2017) [19] | Observational study | Online health information for patients with polymyalgia rheumatica | Readability using the Flesch Reading Ease and SMOG Readability tools.  8-item Credibility Indicator (incorporating authorship, affiliation, editorial team, date of creation, date of update, backing, accreditation and financing). | Of all websites identified (n=52) the mean (SD) Flesch Reading Ease and SMOG Readability scores were 48 (15) and 10 (2), respectively.  The mean (SD) Credibility Indicator was 2 (1).  50 (96%) of websites were accurate.  No P values stated |
| Harris VC et al. (2018) [56] | Cross sectional descriptive | Evaluation of leading online content on tympanostomy tube placement. | PEMAT understandability and actionability scores | PEMAT scores found all sites (n=10) were understandable, mean=81.9%  Seven of the sites has low actionability score, mean=44.6%.  No P values stated |
| Maciolek KA et al. (2017) [20] | Observational study | Prostate Biopsy Online Patient Education Materials. (PEM) | Readability was assessed Flesch-Kincaid Grade Level. Understandability and actionability were measured using the Patient Education Materials Assessment Tool (PEMAT). | 31 (21%) sites met the recommended <8th grade reading level.  The PEMAT understandability score for academic institution sourced PEM was higher than private (P = .02) and those unaffiliated with urologists (P = .01). |
| Siddhanamatha HR et al. (2017) [21] | Observational study | Websites providing educational content for patients with rheumatoid arthritis. | Accuracy, completeness, technical elements, design and aesthetics, readability, usability, and accessibility of the websites | Of 46 websites in total, 98% provided accurate information.  The mean (SD) reading level was grade 12.1 (2.3).  78% were easy to navigate but only 33% were friendly for people with visual and/or hearing impairments.  No P values stated |
| Nielsen-Bohlman L et al. (2004) [47] | Observational Study | An evaluation of health literacy in the U.S. and formulate solution to overcome associated obstacles. | Current level of readability of online content. | Over 300 studies indicate that health-related materials exceed the average reading grade of U.S. adults.  No P values stated |
| Chin J et al. (2018) [48] | Observational Study | Improve patient understanding of online content pertaining to adults with hypertension. | Information retention and comprehension | Revised passages yielded improved retention and comprehension, with less reading time required per unit uptake of information also noted. Methods included simplifying language and signalling clear organisation.  On average, participants were found to significantly better remember the revised passages (*M*ean = 0.74, *SD* = 0.14) compared to the typical passages (*Mean* = 0.70, *SD* = 0.11, *p* < .01). |
| Boudewyns V et al. (2015) [49] | Randomised Controlled Trial | Web based information handouts | Information comprehension and application | Individuals who received the revised and improved online formats had higher comprehension scores than those who received the MedGuide (*p* < 0.001). |
| Morrow DG et al. (2005) [50] | Observational Study | Patient-centred medication instructions in order to empower patients to plan a medication taking regimen. | Information comprehension and retention, health related literacy and verbal working memory. | Patient-centred instructions were more accurately understood for unfamiliar medications (p <0.05)  The standard instructions were more accurate for familiar medications (p <0.05) |
| Pander Maat H et al. (2010) [51] | Observational Study | Revision of patient information leaflets | Usability, speed of information retrieval and comprehension. | Once located, comprehension of the information was around 90%.  Revisions led to better performance. Information was found more quickly. Comprehension scores were also improved.  No P values stated |
| 1. Discussion Boards/ online groups | | | | |
| Cedars BE et al. (2019) [22] | Qualitative and thematic analysis | Online discussion boards for urethral stricture disease and urethroplasty | To describe the patient experience and chief concerns with urethroplasty to improve physician understanding and patient education. To understand how men, use online discussion boards and what information is available about urethroplasty. | Problems in navigating the healthcare system with Urethral Stricture Disease (USD) (n = 141) and weak urine stream (n = 70) were the most frequent pre-urethroplasty complaints.  Patients participated in online discussions to share experiences with USD and urethroplasty, share emotional support and search for answers.  No P value stated |
| Teaford D et al. (2019) [23] | Descriptive statistics and qualitative content analysis | New mothers' experiences with online postpartum forums. | To explore women's experiences with an online forum during the postpartum period. | Five themes were produced through data analysis: 1) social support; 2) anonymity; 3) in-groups; 4) drama; and 5) entertainment/pastime.  Participants found that the discussion board could facilitate sharing of information, act as an entertainment source and provide community.  No P values stated |
| Castaneda P et al. (2019) [24] | Qualitative study | eHealth Peripheral Artery Disease (PAD) Community Forums | Original posts and related responses were analysed for thematic content | Themes identified included: medical advice (40.5%), personal experiences with PAD (32.8%), and social support (12.6%). Negative attitudes were discussed in 10 of 18 (55.6%) posts related to poor experiences with health-care providers. 15.1% of medical advice was inconsistent with clinical treatment guidelines.  No P values stated |
| 1. Video | | | | |
| Bae SS et al. (2018) [12] | Observational study | YouTube videos in the English language as a patient education resource for cataract surgery. | 14 criteria important for educating patients about the procedure. | The mean (SD) number of usefulness criteria satisfied was only 2.28 (1.80) out of 14.  There was no significant difference in view count between the most useful videos and other videos (p = 0.94).  Videos from medical bodies such as the National Health Service were found more useful in terms of patient education (p < 0.0001). |
| Pedersen MM et al. (2019) [25] | Feasibility study | Development of a preventive educational video for patients exposed to whiplash trauma | The development followed a systematic approach and was theory-driven supplemented with available empirical knowledge. | Participants (n=4) felt the content was ‘relevant, helpful, and reassuring to watch.’  All four preferred video content instead of written material.  No P values stated |
| Finnegan G et al. (2018) [26] | Case study | An online vaccine communication project (textual, videos and infographics) | Case study of a pro-vaccine information hub launched in 2011. Vaccines Today provides high-quality information about vaccines and diseases, expert interviews, answers to frequently asked questions, parent/patient stories and videos/infographics. | Two categories of informing patients were found to work well:  1) The story telling approach  2) Answering questions posed by patients  No P values stated |
| Button K et al. (2018) [27] | Mixed methods study (Qualitative and feasibility study) | A web-based intervention (TRAK) that provides knee patients with health information | Testing the TRAK intervention in physiotherapy patients to gain their subjective insights into its use | Participants reported that TRAK was easy to use overall. Basic internet skills were all that were required.  Using TRAK in adjunct to physiotherapist management increased patients' understanding and confidence.  No P values stated |
| Vogel H et al. (2018) [28] | User survey | Video-assisted patient education (VaPE) in anaesthesia | The content of the videos, the technique of video presentation, usefulness of VaPE  Interviews carried out with patients and physcians | 97.5% of anaesthetists (n=80) found VaPE useful for patient education  92.5% observed time saved for the following interview  96% stated that watching the video left patients better informed.  Increased anxiety caused by VaPE was noted by 46%, 54% found no such effect.  No P values stated |
| Pithadia DJ et al. (2019) [29] | Cross-sectional study | YouTube videos as a source of patient information about phototherapy and excimer laser for psoriasis | Assess the educational quality of YouTube videos about phototherapy and excimer laser for psoriasis | 11.2% of videos contained high-quality patient educational information 2.5% were fair quality, and 66.1% were low quality.  Thirty-five (28.2%) videos provided background information regarding psoriasis. Of these, 28 (80.0%) contained evidence-based content about the epidemiology, systemic involvement, genetics, and immune nature of psoriasis.  Seven (20.0%) presented non-evidence-based claims and high mortality rates associate with psoriasis  No P values stated |
| Ferhatoglu MF et al. (2019) [31] | Observational study | Sleeve Gastrectomy Videos Shared on YouTube | The popularity of the videos was evaluated with the video power index (VPI). Educational quality of videos was measured using the DISCERN score, Journal of American Medical Association (JAMAS) benchmark criteria, and Global Quality Scores (GQS). The technical quality was measured by Sleeve Gastrectomy Scoring System (SGSS) | DISCERN, JAMAS, GQS, and SGSS evaluations of academic sourced videos yielded significantly higher scores than the patient sourced videos (*p* < 0.001, *p* < 0.001, *p*: 0.001, *p* < 0.001, respectively).  However, Video Power Index evaluation of patient sourced videos yielded significantly higher scores than academic and physician sourced videos (*p* < 0.001, *p*: 0.003, respectively)  Negative correlations between video power index and JAMAS, GQS, and SGSS scores were found. |
| Erdem H et al. (2018) [32] | Observational study | Bariatric surgery videos (n=175) on YouTube | Usefulness of bariatric surgery videos on YouTube - A usefulness score (very useful, useful or not useful), as previously described by Lee et al., was slightly modified. | 53.7% were useful and 24.6% were very useful. No videos were found with misleading information.  A Spearman’s rank correlation found no significant correlation between the usefulness score and number of views (*r* = − 0.118, *p* = 0.121), number of likes (*r* = − 0.038, *p* = 0.614), number of dislikes (*r* = − 0.003, *p* = 0.972) or video length (*r* = − 0.106, *p* = 0.161). |
| Biggs TC et al. (2013) [33] | Observational study | YouTube as a source of information on rhinosinusitis | Videos (n=100) were graded on their ability to inform the lay person about rhinosinusitis. | 45% of the videos were deemed to provide some useful information. 55% of the videos contained little or no useful facts, 27% of which contained potentially misleading or even dangerous information. Videos uploaded by medical professionals or those from health information websites contained more useful information than those uploaded by independent users.  No P values stated |
| Kwok TMY et al. (2017) [34] | Observational study | Videos available on YouTube pertaining to interventional treatment for varicose veins. | Informational and scientific quality (good, fair, poor) and stance (for, neutral, against, unclear) toward the treatment option discussed, treatment type and video source | The largest group of videos (47.3%) received a quality rating of fair, meaning that they discussed one or two aspects of a treatment option, such as procedural technique and indications. Among those videos rated poor (25.0%), nearly all videos (98.2%) failed to mention a specific treatment.  No P values stated |
| Bademci M et al. (2017) [35] | Observational study | YouTube videos on deep venous thrombosis | Scientific content, accuracy, and currency | Although most of the videos uploaded (22.9%, n = 111) were created by physicians, the number of views for website-based videos was significantly higher (p = 0.002). When the uploaded videos were assessed in terms of their usefulness, videos from physicians and hospitals were statistically more useful than other videos (p < 0.001). |
| 1. Visual/ Pictographs | | | | |
| Christensen C et al. (2017) [30] | Pilot study | Doodle Health: A Crowdsourcing web-based game for the Co-design and Testing of Pictographs to Reduce Disparities in Healthcare Communication. | To test the usability of the game and its appeal to healthcare consumers in the co-design and evaluation of pictographs. | Initial testing indicates crowdsourcing is a promising approach to pictograph development and testing for relevancy and comprehension. Over 596 drawings were collected, and 1,758 guesses were performed to date with 70-90% accuracy.  No P values stated |
| 1. Device on which content is accessed | | | | |
| Gogovor A et al. (2017) [36] | Literature review and qualitative focus group study | Development of an Internet-based chronic pain self-management program | Information needs and gaps in chronic pain (CP) management as well as technology features to inform the development of an Internet-based self-management program | Gaps identified in terms of CP management included lack of knowledge, limited access to health care, substandard care and scarce self-management support.  Focus group themes included patient education on chronic pain care, attitude-belief-culture, financial and legal issues and motivational content.  No P values stated |
| LüchtenbergM et al. (2008) [37] | Observational study | Websites containing medical information addressing laymen or patients (n=139) | Accessibility using a quantitative checklist which is based upon the Web Content Accessibility Guidelines of the World Wide Web Consortium (W3C) | 18% (15) of sites were categorised as WAI (Web Accessibility Initiative) level A or AA.  WAI level AA was reached by 1% (1) of the web sites.  None of the web sites reached level AAA  82% of the assessed consumer web sites were not completely accessible to the visually impaired.  No P values stated |
| Bashi N et al. (2018) [38] | Systematic review | Patient educational interventions using mobile apps | The reporting quality of studies was assessed according to the mobile Health evidence and predefined reporting assessment criteria. | Of 15 studies, none reported on the data security, privacy, and confidentiality measures.  No P values stated |
| Noel W et al. (2017) [39] | Prospective cohort study | A mobile medical application was developed to improve postoperative plastic surgery patients care | The content, design, and efficacy of the application assessed by questionnaire (n=60). | Participants reported that questions regarding postoperative management were addressed effectively with a mean score of 4.1/5.  Most participants recommended the application to plastic surgery patients with a mean score of 4.6/5.  The application’s information prevented 12 patients from calling the plastic surgeon or the emergency department unnecessarily.  No P values stated |
| Nicholas J et al. (2015) [40] | Systematic review | Mobile apps for bipolar disorder | Comprehensiveness and quality of information was assessed against core psychoeducation principles and current BD treatment guidelines.  Management tools were evaluated with reference to the best-practice resources for the specific area.  General app features, and privacy and security. | Informative apps covered over a third (4/11, 36%) of core psychoeducation principles and 2/13 (15%) best-practice guidelines.  A third (10/32, 31%) cited their sources.  ‘Neither comprehensiveness of psychoeducation information (r=-.11, P=.80) nor adherence to best-practice guidelines (r=-.02, P=.96) were significantly correlated with average user ratings.’ |
| Jamison RN et al. (2017) [52] | Randomised Controlled Trial | To test an app that enables chronic pain patients to assess, monitor, and communicate their status to their healthcare provider. | Frequency of app use and app satisfaction scores | 78.1% of participants (n=105) reported daily using the app.  Patient satisfaction survey results:   * Ease of use: 1.8/10 (0=very easy to use, 10=unusable) * Willingness to use post-study: 2.4/10 (0=very willing, 10=unwilling.   Participants with more daily assessments reported higher app satisfaction (P<0.05) compared with those that used the app less. |
| Schulz PJ et al. (2007) [41] | Randomised Controlled Trial | Website designed to enhance self-management in chronic lower back pain | Change in pain levels, change in knowledge, behavioural changes and medication use. | Users accessed the website on average 11.5 times during the 5 month study.  Mean pain levels fell in the control group from 5 to 3.9 (10=most severe pain imaginable, 1=no pain) whether as control group remained largely the same (6.1 to 6.3)  No P values stated |
| Caiata Zufferey M et al. (2009) [42] | Observational study | Website ‘Oneself’ designed to promote self-management and inform patients on lower back pain management. | Self-comprehension,  Improvement of vocabulary, exercises knowledge, self-confidence and motivation. | Of all the survey participants (N = 129) 25% reported that ONESELF increased their knowledge about back pain  Successful testimonials indicated self-management was encouraged.  No P values stated |
| Hagerman CJ et al. (2017) [43] | Observational study | Decisional Aids (DAs) for low-risk Prostate Cancer (PCa) patients | What are the informational needs of low-risk PCa patients and what are the essential aspects of treatment DAs that increase likelihood of physicians recommending them to the patient? | Semi-structured interviews found: ‘Physicians highlighted the importance of patient education and described the characteristics of a low-risk PCa DA that would increase the likelihood of its use in clinical practice.’   * Encourage patients to take their time in decision making * Frankly inform on post-treatment side effects   Incorporate physician recommendations on content and mode of delivery.  No P values stated |
| Kim MI et al. (2002) [44] | Observational study | Website comprising of a situational approach to the organisation of disease-specific patient information. | Interface usability, personal relevance of retrieved information, comprehension of retrieved information. | Responses (n=37) yielded high ratings for:   * interface usability (4.6/5) * personal relevance of information found (4.7/5) * comprehension of information (4.8/5)   No P values stated |
| Meppelink CS et al. (2015) [45] | Observational Study | Colorectal Cancer screening messages divided into high literacy and low literacy groups with and without illustrations. | Information recall, attitudes, intention to undergo screening. | Spoken messages about colorectal cancer screening improved recall (*P*=.03) and attitudes (*P*=.02) when compared to written messages in lower health literacy individuals.  Animations alone failed to improve recall, but when combined with spoken text, they significantly improved recall (*P*=.02). |
| Mayer RE et al. (2003)[46] | Literature review | A theory designed to format multimedia content in order to optimise patient education | Overloading, Speed of content delivery and misalignment of textual and visual cues. | Narration has better transfer of information than on screen text  Learner controlled segments increase transfer of information  Graphics and corresponding text should be aligned visually  Signals also improve transfer  No P values stated |
| Stage of patient journey | | | | |
| Biernatzki L et al. (2018) [58] | Cross sectional descriptive | Evaluation of the informational needs of diabetics. | 'treatment-process', 'course of disease', 'abnormalities of glucose metabolism' and 'diabetes through the life cycle'. | Information needs amongst diabetics is poorly investigated although in high demand.  No P values stated |
| Boyde M et al. (2009) [59] | Observational study | An investigation of the learning style and learning needs of heart failure patients. | Questionnaire identifying preferred learning modalities. | 64% of participants (n=55) reported a preference for multimodal learning style  18% preferred textual information  11% preferred auditory  and 7% preferred kinaesthetic.  Signs and symptoms were ranked as the most important topics to learn about  No P values stated |
| Hagenhoff BD et al. (1994)[60] | Systematic Review | Evaluation of the perceptions of both patients and nurses on the importance of educational content for patients with Congestive Heart Failure (CHF). | Questionnaire evaluating the importance of the following categories:  Anatomy and physiology; Psychology; Risk Factors; Medications, diet and activity; other. | Patients and nurses rated all information as moderately to very important to learn.  Patients often rated information as more important than nurses did.  No P values stated |
| Wehby D et al. (1999)[61] | Descriptive Comparative study | Perceptions of Regional Nurses (RNs) and patients concerning educational content on Heart Failure (HF) were analysed. | Ranking of categories of HF education in order of importance by patients and RNs. | ‘Patients perceived the subscales of general HF information, risk factors, medications, prognosis, and signs and symptoms as more important to learn than the RNs did (P <.05).  Patients perceived diet information as less important to learn than the RNs did (P <. 05).  Patients perceived all 8 subscales as more realistic to learn than the RNs did (P <.05). Although not in identical order, both groups ranked education related to medication and signs and symptoms as the 2 priority areas.  Diet information was ranked eighth by the patients and third by the RNs.’  No P values stated |
| Clark JC et al. (2004)[62] | Descriptive-correlational study | Examination of perceived learning needs of Heart Failure patients post-discharge. | ‘The Outpatient Heart Failure Learning Needs Inventory was used to rate subjects' perceptions of the importance of educational topics on a five-point Likert scale.’ | ‘Findings indicated that subjects perceived signs and symptoms and medications as most important to learn and diet, activity, and psychological factors as least important to learn. These findings are consistent with previous research and provide a framework on which to base the development of educational programs for patients with heart failure. A significant finding was that nearly 25% of screened patients were unable to participate because they were unaware that they had been diagnosed with heart failure.’  No P Values Stated |
| Kiliç B et al. (2015)[63] | Descriptive Comparative study | Qualitative analysis of questionnaires examining Perceptions of Regional Nurses (RNs) and patients concerning educational content on Heart Failure (HF) were analysed. | (1) Themes related to the educational needs of patients about usage of drugs.  (2) Themes related with lifestyle changes. (3) Themes about the educational needs of the patients related to the characteristics of the disease Ranking of categories of HF education in order of importance by patients and RNs. | ‘In this study HF patients stated that they mainly need information about the effects and purposes of the drugs they used. The need for information about the management of the symptoms that affect daily activities are considered 2nd and the educational needs about the disease itself are considered 3rd in importance.’  No P Values stated |
| Solomon P et al. (2018) [65] | Qualitative study | To build an evidence based online patient information resource for HIV patients | Transcribed interviews of stakeholders underwent qualitative content analysis | Interviewees suggested descriptions of all members of the healthcare team involved with HIV care be included in the website  It was also suggested to organise the menu into health challenge categories for ease of navigation  No P values stated |
| Liu XL et al. (2017) [64] | Umbrella review | Aimed to identify the current evidence on health education-related interventions for patients with acute coronary syndrome (ACS) or type two diabetes | Clinical outcomes, behavioural outcomes, psychosocial outcomes and medical service use. | Nurses and multidisciplinary teams were the most frequent healthcare professionals to provide education, and most educational interventions were delivered after discharge.  Face-to-face sessions were the most common delivery formats of patient educational interventions.  Psychoeducational interventions were found to be effective in reducing smoking and admissions for patients with ACS.  No P values stated |
| Credibility and Completeness | | | | |
| Boyer C et al. (1998) [53] | Review | Review of ‘HONcode’, a guideline designed to raise the quality of online patient education data. | Guidelines to information providers, with the aim of raising the quality of online data available and helping to identify websites that are maintained by qualified people and contain reliable data. | The HONcode mainly includes the following ethical aspects: the author's credentials, the date of the last modification with respect to clinical documents, confidentiality of data, source data reference, funding and the advertising policy.  No P values stated |
| Priyanka P et al. (2018) [54] | Observational study | Evaluation and analysis of online content pertaining to oesophageal duodenoscopy for patients. | Global Quality Score, Health on Net, Flesch-Kincaid Reading Ease (FRE) and Flesch-Kincaid Grade level (FKG) | 3 websites were found to have high quality, comprehensive and authentic information. These websites were: https://www.healthline.com, https://www.uptodate.com, and <https://www.emedicine.medscape.com>.  13 sites yielded moderate quality of information. The mean Flesch-Kincaid Reading Ease (FRE) score was 46.92  The mean Flesch-Kincaid Grade level (FKG) was 11th grade  No P values stated |
| Couper MP et al. (2010) [55] | Cross sectional survey | Analysis of the perceived importance of sources of health information online | Ranking of sources in terms of reliability and influence; Use of internet in age groups. | Internet use was more common at younger ages, increasing from 14% among those aged 70 and older to 38% for those aged 40 to 49.  Internet users rated health care providers as the most influential source of information for medical decisions, followed by the Internet, family and friends, and media.  No P values stated |
| Volk RJ et al. (2013) [57] | Cross sectional survey | Evaluation of ongoing studies into what the standards for Decision Aids for patients should be. | Voting system to develop criteria for decision aid standards. | The review comprised 13 manuscripts on topics including current frameworks used to create healthcare content, health literacy and the role of patient stories  No P values stated |

**A screenshot of a cell phone

Description automatically generated**

Figure 3. Infographic framework for ‘Modes of Engagement’ for online healthcare content.

# Discussion

In today’s world of access to knowledge often being initially online, it is of importance for healthcare professionals to be able to create effective content. We performed a wide scoping literature review to identify features which may improve quality of engagement with online healthcare content. Using these results, we have developed a framework (fig 3) to facilitate the development of online patient healthcare content. All but one category was reported on by three or more papers except the Visual/ Pictograph category. This was included following discussion amongst authors as it was felt to be a relevant and an important means of communicating information. Although the features identified are, on reflection, intuitive, the framework arms the content creator with the best available strategies in making the content engaging and hence effective.

Other similar frameworks such as the International Patient Decision Aid Standards (IPDAS) [57] and the Standards for Universal reporting of patient Decision Aid Evaluation studies(SUNDAE) checklist [72] have been developed for the evaluation of Decision Aids. However, to the best of our knowledge, this is the first framework of its kind to specifically focus on engagement with online content rather than a checklist approach to ensuring decisions are made with appropriate consideration to all relevant issues and options. Knerr et al. [66] published a study design aimed at evaluating patient behaviour in response to a patient decision aid based on IPDAS standards but has not reported results. Although patient decision aids can be a form of online content, up to now, efforts have been directed towards ensuring transparency and trust in imparting information rather than the ability of online material to engage the user [73]. The need to engage people in healthcare content has been overlooked. We propose that this framework is used to improve engagement which in turn will improve adherence with medical treatment and hence improved outcomes. Nevertheless, the rigorous process used by the IPDAS and SUNDAE developers is one which we would be interested in following in refining and adapting the framework arrived at through this literature review.

Further work will involve a co-design process with all stakeholders (including patients) to refine the insights we have gained from the literature regarding engagement with online content. Personalisation of healthcare content may have bearing on the issue of engagement. Studies have shown that it is possible to ‘segment’ the population according to likelihood to respond to healthcare messages [74,75]. Although our framework provides the best evidence available relating to engagement with online content, the holy grail may lie in developing further the field of psychographics for healthcare. Although researchers have investigated the way segmentation affects a defined intervention, the effect of segmentation itself is yet to be assessed in a meaningful manner [76] The modern internet is able to bring together varied but related content using the concept of the semantic web and application of folksonomies [77]. The confluence of Web 3.0 (to crowdsource content relevant to a desired healthcare behaviour), psychographic segmentation (including segmentation based on the proposed framework) and machine learning may provide a way forward. We have developed a Web 3.0 healthcare content platform ([www.health-shared.com](http://www.health-shared.com)) and intend to use it for this purpose.

## Limitations

The principle limitation to this works is the fact that the majority of this suggested framework is not supported by strong evidence. Studies were heterogenous in terms of aims, interventions and outcomes, with poor methodological quality. Despite this, the components of the framework are intuitive, and we believe that its application may be beneficial. Another potential limitation of this work is that our framework has not yet been evaluated by stakeholders including patients, clinicians and content creators.

## Conclusions

There is paucity of high-quality data relating to factor which improve quality of engagement with online healthcare content. Our framework summarises the reported literature which may be useful to healthcare content creators. Evaluation of the utility of online content to engage users is of significant importance and may be accessible through tools like the Net Promoter score. Web 3.0 technology and development of the field of psychographics for healthcare offer further potential for development [75]. Future work may also involve improvement of the framework through a co-design process.

Although there are often specific healthcare issues needing to be addressed in response to crisis situations, we believe that this work is more generally important in facilitating patient activation and patient supported self-management which are two major pillars in how healthcare systems needs to realign in order to keep up with increasing demand.

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UJ conceived idea, LA, EA, AA, NH, SL and PN wrote manuscript, UJ, LA and PN reviewed and edited manuscript.

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### Conflicts of Interest

UJ is the founder of [www.health-shared.com](http://www.health-shared.com).

## Abbreviations

HON - Health On the Net

JAMAS - Journal of American Medical Association

MEDLINE - Medical Literature Analysis and Retrieval System Online

MeSH - Medical Subject Headings

PEMAT - Patient Education Materials Assessment Tool

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses

RCT – Randomised Controlled Trial

WAI - Web Accessibility Initiative guidelines

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