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Original Paper

# The Diabetes App Challenge: User-Led Development and Piloting of Internet Applications Enabling Young People With Diabetes to Set the Focus for Their Diabetes Consultations

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## Abstract

**Background:** Traditionally, some teenagers and young adults with diabetes have not engaged well at diabetes appointments, giving rise to concerns about long-term health risks. We considered that apps might help this group of patients to improve preparation for, and therefore engagement at their appointments. Although there are already many apps for young people with type 1 diabetes (YPD), we thought that by supporting YPD themselves to develop apps, the resulting products would have greater “authenticity” and relevance.

**Objective:** To test the feasibility of an online competition to (1) recruit and support YPD to develop apps (mobile or Internet based) to help prepare for clinic appointments, and (2) for these apps to be tested and rated by YPD.

**Methods:** The “Diabetes App Challenge” was a United Kingdom (UK) national competition, run between June and October 2012 for teams including at least one YPD (aged 16-25) to pilot the design and development of apps for use by other YPD prior to clinic appointments. The competition was advertised by social media, email, AdWords and postings on the Diabetes UK website. Registrants for the competition were supported via email and discussion forum. After app development, other YPD were invited (November 2012-February 2013) to trial the apps, choose and use one prior to a clinic appointment, and review their experiences.

**Results:** Of 56 people (including 28 YPD) who expressed interest in the competition, 6 teams (14 people) developed and submitted an app. Two apps aimed to facilitate agenda setting in clinic consultations, 2 enabled data logging and 2 helped insulin dose calculation. Of 135 YPD who registered to trial the apps, 83 (61.5%) took part (mean age 18.98, 37/83 male). Agenda setting apps were considered most useful for preparing for and setting the focus of clinic appointments ( $P=.02$ ). Just over half (46/83, 55%) said they would use their chosen app again and 4/5 (67/83, 81%) would recommend it to a friend.

**Conclusions:** This competition to engage YPD in developing and reviewing apps proved successful. App designers and testers saw a need for a range of functions. However, this may, in part, reflect a lack of detailed knowledge of all existing apps and be limited by the technical skills of YPD. App competitions appear worth applying to other patient groups, but future competitions should include a review stage and perhaps focus on ideas for app design for subsequent professional implementation.

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## KEYWORDS

Type 1 diabetes; adolescents; mobile technology; clinic appointment; user-innovation; self-care; user-centered design

## Introduction

There is widespread interest in harnessing the potential of apps to promote better self-care of young people with type 1 diabetes (YPD). However, websites and apps are likely to be most popular if they really engage and interest patients in terms of both style and content [1]. Programmers working with user representatives are likely to optimize such recipient-app “fit” but differences of language, attitudes, and values may remain a problem [2], and programmer-led rather than patient-led app development may inhibit innovation. Problems may be minimized if developers themselves are drawn from user communities; mobile “platforms” are becoming easier allowing users with limited skills to customize and create their own innovative designs [3]. This approach has been tried before in user-led competitions inviting user submitted designs to be trialled and reviewed by other users [4-7] but not with YPD.

Many YPD demonstrate poor blood glucose control [8], which if sustained, is the strongest risk factor for the development of future complications [9] and reduced life expectancy [10]. Helping YPD engage with health services, to manage their condition and achieve better diabetes control is essential [11]. Health care professionals need to connect with a wide range of differently-motivated YPD to help them cope with diabetes and achieve optimal diabetes control [12]. It is thought that a stronger emphasis is needed on “patient-centered” consultations for YPD [13], and finding innovative ways to enhance the active involvement of YPD in agenda-setting in diabetes consultations and engaged self-management [14]. User-centered apps that may improve blood glucose monitoring have been piloted [15], yet to our knowledge, although there is (locally) current pilot work on web-based pre-clinic agenda setting for adults with diabetes [16], there were no apps aimed at YPD for consultation engagement.

The objective of this study was to evaluate a new way to engage YPD in designing and producing apps to improve engagement at diabetes clinic appointments. The aim of the Diabetes App Challenge was to test the feasibility of using a UK national online “competition” to (1) recruit and support YPD to design and develop apps to help set the focus for diabetes consultations, and (2) recruiting other YPD to test these apps.

## Methods

### Ethics

Ethical approval for the study was granted (12/SW/0121, 28<sup>th</sup> May 2012) by the Cornwall & Plymouth National Research Ethics Service Committee of the National Health Service (NHS).

### Design and Sample Size

#### Overview

The study comprised 2 stages: (1) a UK competition in which YPD and teammates (“developers”) developed an app; and (2)

YPD (“reviewers”) were invited to test and review the submitted apps. We could not predict how many apps would be submitted but anticipated up to 10 entries and had one app developed before the competition via a student project. This app was available (1) as an example for other developers, and (b) as one entrant for the competition and for review. In stage two, our target was to recruit up to 200 reviewers.

### Stage 1 Developers

Developer teams had to include at least one person aged 16-25 with type 1 diabetes living in the UK. Various online methods were used to raise awareness of the competition. Interested parties were directed to the project website for participant information, consent, and registration (Figure 1). Methods included: (1) email to 416 pediatricians and adult diabetes consultants and 160 computer science lecturers of UK universities following online searches for contacts; (2) 68 messages posted on university computer science, students union and diabetes relevant Facebook and Twitter pages; (3) paid advertisements set up via Google AdWords (800 GBP) and Facebook (900 GBP) Campaigns; (4) Diabetes UK postings on their website, Facebook, newsletters, and Balance and Update magazines; (5) project and personal Facebook and Twitter pages of the team, project advisory group, and other supporting members; (6) press releases and website posts by the host Universities; (7) posts in diabetes discussion forums; (8) emails to listserves and contacts of the team.

Following expression of interest by email from YPD without app developing experience, and from app developers without diabetes, an email “match-making” service was offered to facilitate the creation of appropriate teams by the first author (EA). Teams were given links to useful resources, tips and suggestions, and were offered technical support through a website forum.

The developers’ challenge was to create smartphone apps or websites that would be useful in preparing YPD for clinic appointments and help set the focus of the consultation. Applicants were shown the example of the first entrant website You + Your Diabetes [17], created by a YPD as a student project in Plymouth University. This used an agenda setting approach with prompts for topics. Regular emails were sent to teams to ascertain progress, answer queries and signpost the forum for more information, discussion and technical support. Teams submitting apps to the competition were awarded 65 GBP towards their publishing and hosting costs, 100 GBP for maintaining their app over the course of the project, 6 GBP for each reviewer that chose their app from a maximum (target) of 200 reviewers and a certificate of achievement. Advertising and competition ran from June to October 2012.

Submitted apps were reviewed by the project team for suitability and accuracy before offering to YPD reviewers in stage two. Developers maintained and updated their apps through stage two and were able to monitor feedback from reviewers in the forum.

**Figure 1.** Screenshot of developer stage website homepage.



**The Diabetes App Challenge**  
 Apps developed BY young people with diabetes...  
 ..FOR young people with diabetes

DIABETES APP CHALLENGE 2012

HOME ABOUT DOWNLOAD MORE DETAILS DEVELOPER REGISTRATION CONTACT FORUM

**UK Competition to develop an app for young people with diabetes**

Computer science student looking for a project? Enter the competition by developing an app (a website or Smartphone or tablet app) and get paid up to £1200!!

Create an app to help young people with diabetes plan for their diabetes clinic appointment and help improve health services in the UK!

Everyone welcome to develop an app but main applicant must be a young person with diabetes (age 16-25, living in UK, with insulin-treated diabetes) - whether you are a young person with diabetes looking for someone to help you develop an app, or someone who can develop an app looking to team up with a young person with diabetes - email [emily.ashurst@plymouth.ac.uk](mailto:emily.ashurst@plymouth.ac.uk) and she will see if she can help you find someone

Shortlisted apps will be tested out by young people with diabetes in the second half of the project.

See [DOWNLOAD MORE DETAILS](#) for more information and [DEVELOPER REGISTRATION](#) to register your

**WIN UP TO £1200! FOR YOUR APP!**

### Stage 2 Reviewers

The target audience was initially people aged 16-22 with type 1 diabetes living in the UK and with clinic appointments due within the 4 month recruitment period (Mid November – Mid February 2013). However, from mid-December, due to initially lower than expected registrations the upper age limit was extended from 22 to 25.

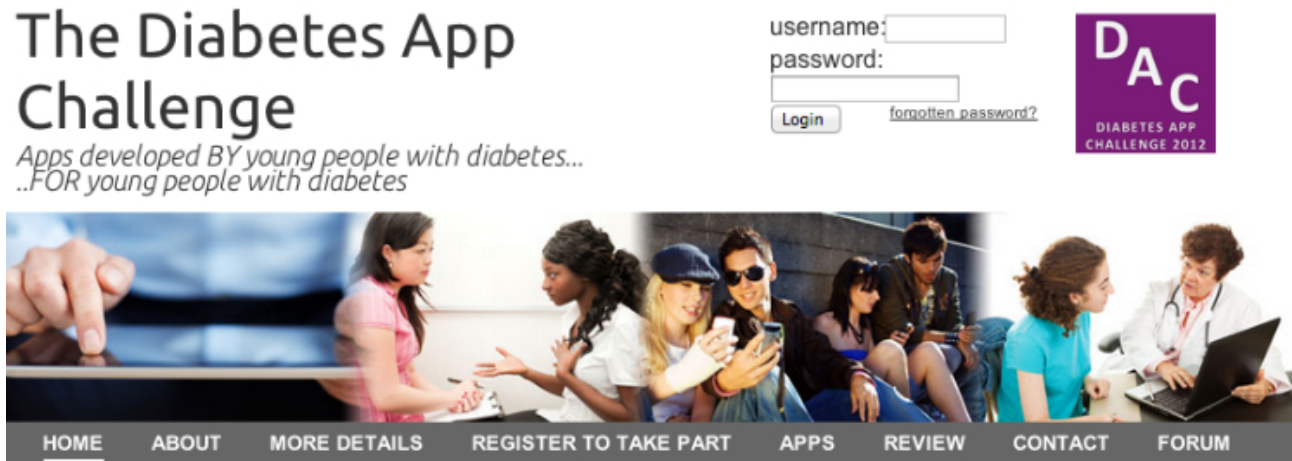
Using similar methods to raise awareness as in stage 1, those previously made aware of the project were contacted with updates of stage 2. In addition, 50 university and 54 GP surgeries were emailed and others contacted by social media. Interested parties were directed to the project website which included

information, consent, and registration for potential reviewers (Figure 2).

Following completion of a baseline questionnaire, those registered were given login access to the website and discussion forum where links to the apps were located. YPD were asked to (1) examine and try the apps on offer, (2) choose one, and (3) use it in preparation for their upcoming clinic appointment (Figure 3). Registrants were advised that apps were not a substitute for medical advice. After the appointment, they were asked to (4) complete a review and follow-up questionnaire, (5) and add comments in the forum. For successfully completing the review questionnaire and posting a minimum of one post in the discussion forum, reviewers were awarded a 20 GBP Amazon voucher via email.



Figure 2. Screenshot of reviewer stage website homepage.



## FREE apps for young people with diabetes!

Help focus your next consultation on what YOU want to discuss

Try out one of the free apps (mobile app or website) on offer for your upcoming diabetes clinic appointment & receive £20 Amazon voucher for reviewing it!

### Register now...

Are you (i) aged 16-22, (ii) living in the UK with (iii) insulin treated diabetes & (iv) have your next diabetes clinic appointment before 21st February 2013?

If so, then all you need to do to take part is download [MORE DETAILS](#) to find out more about the project and fill out the short online form in [REGISTER TO TAKE PART](#)



A big thank you to everyone who developed an app for the Diabetes App Challenge!! Please continue using the discussion forum to hear from those trying out your app

To receive your £20 Amazon voucher we invite you to choose one of the apps, try it out for your upcoming diabetes clinic appointment, complete a short questionnaire and have your say in our forum discussion

### App development

The apps have been developed as part of the Diabetes App Challenge by young people with diabetes and computer science people to help other young people with diabetes plan for and get the best from their diabetes clinic appointments.

Only 113 spaces left for app testers.

**Figure 3.** Screenshot of reviewer stage website app selection.

## Choose an App

1. Have a look at all the apps on offer (click on the icon of each app to view more details & links to the app)
2. Choose **any** app you'd like to try out and install it (or if it's a website, visit the URL)
3. Choose **one** from these and use that app for your upcoming diabetes clinic appointment

You can visit the [forum](#) at any point if you have any queries or technical issues to ask the app developers or tech support

### Diabetes Logger



(iPhone/iPod Touch/iPad)

### Insulin Calc



(Android)

### Diabetes Health Tracker



(Android)

### CPSlider



(web)

### T1NDA



(web/chrome)

### You + Your Diabetes



(web)

## Important information

Some of these apps offer insulin dose calculations, but we ask you to use these with caution and not to replace your current healthcare advice from your doctor or nurse

### Patient and Public Involvement

As well as involving YPD in the development and review of apps, a small group comprising 4 YPD were involved in developing the research project to help ensure it was relevant to other YPD. They helped write and review participant consent forms to ensure accessibility, helped design the Diabetes App Challenge website, created videos to provide further information and were consulted throughout the duration of the project.

### Data Collection

For developers, website registration forms collected demographic data. After participation in the competition, feedback questions regarding competition experience were sent by email and other forum and email communication was collected for content analysis. Those who did not submit an app to the competition (“non-developers”) were followed up by email questionnaire to establish reasons for this and to learn for future competition delivery. For this feedback, non-developers were offered each a 20 GBP Amazon voucher.

For reviewers, the website registration form requested (1) demographic data, (2) next appointment due date, (3) if they had missed or considered missing a clinic appointment and (4) “before-after” questions about satisfaction and confidence (piloting for a subsequent study). After app use, the website follow-up form requested information about the app they used including (1) initial attraction to that app, (2) ease of use, (3) perceived usefulness of the app in preparing for and focusing during their clinic appointment, (4) intentions to use the app

again and recommend to a friend, (5) helpfulness of app features, and (6) follow-up questions. Additional follow-up questions via email included (1) importance placed on YPD-created apps and (2) further qualitative feedback on the Diabetes App Challenge experience.

### Analyses

Descriptive responses to open-ended questions (email and online questionnaire) were analyzed using an inductive method of conventional content analysis to identify and summarize response meanings [18], and repeat occurrences of similar meanings between participant responses were counted and identified as reflecting a common issue of importance in summative content analysis [19].

## Results

### Stage 1 Developers

#### Overview

Six teams (6 YPD and 8 teammates) submitted a completed app to the competition comprising two match-made teams, two self-made teams and two teams of one YPD each (including the “initial” student). Teams were located across England. The 6 YPD had a mean age of 20.33 (SD 3.27) and a mean of 8.75 years diabetes duration (SD 7.36) and the 8 teammates had a mean age of 21.50 (SD 2.73). Half of developers, both YPD and teammates, were computer science university students (7/14), 2 were in computer science employment (14%), 4 were

students in other subjects (29%) and 1 in unknown employment (7%).

In total 56 people registered interest to develop an app. Excluding enquiries with no further interest and offers of support from people without diabetes or technical skills, there were 23 teams of potential developers. These included 9 match-made teams, 11 teams of one YPD and 3 self-made teams. Nineteen teams continued corresponding with EA and 8 teams described plans to develop an app. Of those, 25% who expressed initial interest submitted apps (Figure 4).

Of the 42 potential developers, a third (15/42) were recruited from emails to clinicians, universities, and others, 7 from

Diabetes UK, 4 from Facebook/Twitter, 2 were known contacts of the project, 1 from Google AdWords. A third (13/42) could not be traced to the original advertising source.

Nineteen (68%) of the 28 potential developers who did not submit an app responded to email follow-up. The reasons for not completing an app were lack of time or other commitments (11/19), communication or conflict of ideas within match-made teams (6/19), realization that their design already existed (1/19), and app coding difficulties (1/19). Although incomplete or just ideas, seven made reference to their app plans, including four data-logging, two notes/ agenda setting, and one diabetes game.

Figure 4. Flow diagram showing developer participant numbers from recruitment through to app submission.

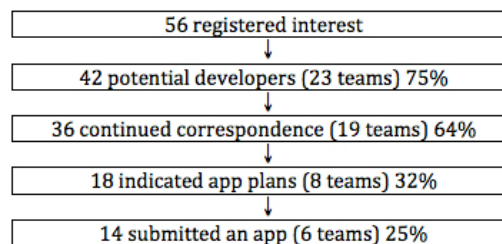


Figure 5. Summary of comments made about apps perceived usefulness (n=61).

**Data recording (Comments from 23/ 31)**  
 Some commented that the data recording apps offered an easier method of recording data by comparison to a paper diary and particularly liked the visual aid for demonstrating blood glucose trends to their doctor or nurse. Some however, felt that adding data (including retrospective data) was a slow process, including one reviewer who noted that an insulin pump or meter already records such data.

**Insulin Calculator (Comments from 16/ 23)**  
 Some commented that the insulin calculator apps were useful for raising discussion with their doctor about concerns of calculating insulin and carbs counting, while some found the apps useful but not relevant for clinic appointments. Some however, felt the apps did not offer convenient data storage and one reviewer noted (again) that insulin pumps already make such calculations.

**Agenda setting (Comments from 22/ 29)**  
 Most commented that the notes/ agenda setting apps assisted reviewers in raising issues or concerns at clinic appointments. In particular, the topic areas of the You + Your Diabetes app helped to identify issues which were usually forgotten. Some felt they were more prepared to think about what they needed to ask or discuss and felt more in control of the appointment. Some however, felt the apps did not offer adequate note saving options for future reference.

**Submitted Apps**

The 6 submitted apps were, Diabetes Logger [20], Diabetes Health Tracker [21], You + Your Diabetes [17], T1NDA [22], Insulin Calc [23], and cpSlider [24]. The main functions of the apps were: (1) recording and viewing data; (2) helping calculate insulin dosage; and (3) making notes/ agenda setting. Of these, 2 were submitted on iOS, 2 for Android and 3 were websites (Table 1).

**Support and Communication**

Across the course of the project EA sent an average of 43 emails to each developer (competition information, requests for progress updates, responses to queries and technical support,

updates throughout reviewer stage and payments). Developers sent EA 12 emails each (updates on progress, queries, and feedback regarding the Diabetes App Challenge experience). Two teams requested support regarding formula accuracy of insulin dose calculations, and one team technical support regarding coding. The most common difficulty cited for developers was time, mostly limited by university assignments or employment. Other difficulties included design and technical skills and team communication.

**Reasons for Creating the Apps**

YPD developers took part in the competition to make it easier for others to manage their appointments and condition, as well teammates gained app project experience (Textbox 1).



**Table 1.** Main functions and platforms of submitted apps and number of reviewers who chose each app.

App name	Device	App function			Reviewers choosing
		Data recording	Insulin dose calculator	Notes/ agenda setting	
Diabetes Logger	iOS	✓			25
Diabetes Health Tracker	Android	✓			6
Insulin Calc	Android/ iOS		✓		17
CPSlider	Website		✓		6
T1NDA	Website			✓	5
You + Your Diabetes	Website			✓	24
Reviewers choosing		31	23	29	83

**Textbox 1.** Reasons for app function design by five YPD developers.

“I have had problems in the past with showing my BG results to consultants and have had problems recording them”

“there is absolutely no point whatsoever in going to a diabetic clinic appointment at a hospital without an accurate record of blood sugar etc. as there is really very little anyone can do for you without it”

“keeping track of lots of data was a real pain, and having to do so to make the consultations useful, quite time consuming”

“The main reason for me to want to make this app was in the hope that it would help someone with their new diagnosis”

“I was motivated by the challenge of deigning an app for people like myself, who have type 1 in the hope that in some way it would make there life better of easier”

## Stage 2 Reviewers

### Overview

Of the 135 YPD reviewer registrants, 83 (62%) took part in trialling and reviewing an app. Reviewers' mean age was 18.98 (SD 2.58), 55% were female, and mean years since diagnosis was 7.08 (SD 5.05) ranging from 2 months to over 20 years. Fifty-one (62%) had attended a clinic appointment within the last 3 months, 27 (33%) within 4-8 months, 4 (5%) over 9 months ago. Twelve (14%) had missed, and 19 (23%) had considered missing clinic appointments at some time because they did not think it was worth attending, while 47 (57%) had never considered it.

Reviewers were made aware of the Diabetes App Challenge through (1) Diabetes UK (22/83), (2) Twitter (14/83), (3) Facebook (13/83), (4) word of mouth from friend or family (6/83), (5) email, (8/83), (6) hospital (5/83), (7) newspaper (4/83), (8) doctor's surgery/ letter (5/83), (9) online search (4/83), (10) diabetes discussion forum (1/83), and (11) university news (1/83).

### Reviewer Choice

Reviewers looked at an average of 3 apps each before making a selection (based on self-report and tracking logs). The three most popular apps chosen by reviewers each offered a different function: Diabetes Logger (n=25) a data recording app; You + Your Diabetes (n=24), a notes/ agenda setting app; and Insulin Calc (n=17), an insulin dose calculator app (Table 1).

### Perceived Usefulness of App for Preparing for or Setting the Focus of Clinic Appointment

Over half of reviewers (52/83, 63%) thought their chosen app was useful or very useful for preparing for or setting the focus

of their clinic appointment. Notes/ agenda setting apps were considered more useful (mean 4.10, SD .77) for clinic appointments than data logging (mean 3.36, SD 1.08) and insulin dose calculator (mean 3.22, SD 1.28) ( $F_{2,80}=5.72$ ,  $P=.01$ ). Comments from 61/83 reviewers reflect these scores.

### Intentions to Use Again and Recommend to a Friend

Just over half of reviewers intended to use the app they had chosen again (46/ 83, 55%) and most intended to recommend the chosen app to a friend (67/ 83, 81%). No significant differences were found between app functions and intention to use again ( $P=.52$ ) nor recommend to a friend ( $P=.40$ ). Overall, reviewers indicated that the apps were worth trialling but a few felt improvements or amendments were needed before regular use.

### Ease of Use Per App

Across the apps, there was a significant positive correlation between ease of use and usefulness ( $r_{83}=.45$ ,  $P<.001$ , one tailed). Most reviewers (65/83, 78%) thought their chosen app was easy or very easy to use. This varied from 100% for two apps (You + Your Diabetes and T1NDA) to 33% (27/83) for another. Reviewers' felt the easiest to use apps were self-explanatory and simple to understand. The other apps were also considered easy to use but with some suggestions to improve the user-interface.

### Useful App Features

By app function, the most useful features reported in qualitative feedback were: for data logging apps (1) setting targets and viewing trends, (2) ease of recording and tracking data, and (3) data storage in one mobile location without need for logbook or pen/ paper; for the insulin dose calculation apps (1) simplicity and ease of use, (2) accuracy and trust of calculator, and (3) all



in one calculation (carbs and insulin); for the notes/ agenda setting apps (1) the topic prompts to identify and remember what to discuss at appointment, (2) simple layout and ease of use, and (3) ability to document and review notes.

### ***The Importance of the Apps Being Created by YPD***

Of the 83 reviewers, 34 (41%) responded to additional follow-up. Most of these (n=23, 68%) felt it was important or very important that the apps were created by YPD. In additional comments (91%, 31/34) much importance was placed on app design (not necessarily development) by diabetic peers because of a mutual understanding of the needs, condition and experiences in order for the apps to offer the most accurate features and details. Two reviewers felt that apps created by like-minded people were reassuring (ie, what benefits the developer, benefits the user). A few mentioned the importance of this age group designing the apps from their perspectives; however for other reviewers age was not important as older people with diabetes experience similar issues. A few felt no importance for the apps to be designed by YPD as long as the needs were met, it worked well and looked good, and YPD feedback shaped the design.

## ***Discussion***

### **Principal Findings**

The most important finding of the Diabetes App Challenge was confirmation of the feasibility of recruiting YPD through an online competition in a relatively short space of time, and with optional support, to develop their own apps to improve preparation for diabetes appointments. We had thought that an online competition would be quicker, more cost effective, and involve larger numbers of YPD, than methods based on a user-panel informing the design of professionally developed app [25,26]. We thought the competition approach might be similar to “hackathons” in rapid collaboration generating impromptu innovation and problem solving [27]. The competition successfully produced six submitted and developed apps: Diabetes Logger, Diabetes Health Tracker, Insulin Calc, cpSlider, T1NDA and You + Your Diabetes. Recruiting larger numbers of YPD to test apps online and provide feedback of their experience was also successful, resulting in 83 completed reviews. Therefore, a competition with online recruitment for design and testing compared very favorably with more expensive and time consuming face-to-face methods.

### **Developer Stage**

The need for YPD, and not just professionals, to be involved in app design and development was emphasised by the partly unexpected range of apps submitted. Originally, we had not anticipated data recording or insulin dose calculation apps as among the tools to engage YPD in preparation for clinic appointments. Although notes and agenda setting items were featured within most of the submissions, only one of the five other apps (excluding the student example) had consultation agenda setting as a principal function. However, this might be because the YPD who designed these apps considered technical issues to be paramount in being able to engage fully at their appointments. In support of this, some reviewers commented

that being able to show the doctor their results on a mobile, and others that helping them deal with the problem of calculating insulin doses, gave them more control and so empowered them in the consultation.

Another significant finding was that the user-developer method we employed was considered important by two-thirds of reviewers. The direct “bottom up” process of peer innovation (ie, what benefits the developer, benefits the user) was valued, although some felt a more “professional” interface was needed.

The study also provided useful information about how to advertise and recruit for a competition. The most effective methods of advertising the competition were university computer science department emails and Diabetes UK online, whereas paid online advertising was considered expensive and ineffective, costing GBP 1700, and resulted in only one potential developer recruited.

A range of unexpected findings, challenges and limitations were also evident in this study. A variety of apps already existed for recording blood glucose, help with carbohydrate and calorie calculations [28], and we had not initially thought that these functions would be considered directly important to agenda setting. We did not specifically ask app developers or reviewers about other apps they may have previously used. At least one of our “drop out” developers withdrew when he considered that his idea had already been developed. In the future, it may be more appropriate for an objective independent review to determine whether specific functions are already met by existing apps. However, we note that similar limitations could affect “hackathons”.

The apps that were produced may also have represented the “art of the possible”, since technical ability was cited as a potential limitation to what could be produced. For example, this may have accounted for a lack of any social media element to the apps. YPD may also have been more adventurous in their ideas if others with greater expertise and resources were to create the apps. Therefore, perhaps professional developer collaborations, or competitions in which YPD just submit ideas for design, rather than actually implement apps, could be the best solution in a future competition.

A probable limitation on the number of apps submitted was the time of year in which the competition took place. The study was scheduled to coincide with the UK summer term and holidays with the intention to “capture” students with available time and interest. However, many students still cited university commitments as reasons for non-participation or withdrawal. Our timescale was also limited by the funding and ethical approval, but a competition run earlier in the year may have attracted greater numbers.

### **Reviewer Stage**

We successfully recruited a large number of reviewers, and while we failed to reach the target of 200 reviewers in the time available, we think our pilot study clearly confirms the feasibility of this approach. The main time constraint was the requirement to test apps prior to the next booked diabetes clinic appointment. Without this fixed requirement, and by recruiting

over a longer period, we would have been able to recruit our target of 200 YPD to test apps.

Diabetes UK and social media platforms Twitter and Facebook were most effective for raising awareness to reviewers. Reviewer participants were self-selected, indicating pre-interest in their diabetes management, yet over a third had previously missed or considered missing a clinic appointment. "Did not attend" rates vary from one clinic to another and over time [29] making it difficult to generalise to the UK population [11]. Future recruitment via clinics might reduce self-selection bias, but another important focus for further research is to determine whether "hard to engage" patients might be more willing to engage in research through popular social media channels than clinics.

Reviewers chose evenly between the 3 main functions of the 6 apps which were suited to different YPD needs for (1) remembering what to ask at appointments, (2) simplifying insulin dose calculations, and (3) easier observation of blood glucose trends. As anticipated in the context of the design specification, notes/ agenda setting apps were perceived as most useful for clinic appointment focus and preparation, in particular, their category prompts for stimulating reflection about areas of concern and reminders to raise issues at the appointment. Despite a large market of diabetes-specific apps (via iTunes and Google Play) none that prioritise this function appeared to be available in 2013 [28]. Some included optional note-making features but did not offer question or category prompts. Previous

work suggested that written pre-clinic check sheets may improve question-asking [30] and appointment satisfaction [31] but this has yet to be fully explored using mobile technology.

Lastly, the online user-review method enabled larger scale remote recruitment, comparable to online usability testing, a common method of assessing the user experience of websites and apps [32]. The anonymity of online feedback can also enable expression of opinion from those hard to reach by other face-to-face means [33]. While face-to-face evaluation might have allowed more detailed feedback, the speed and cost of online research methods made them very attractive in this research.

## Conclusions

This pilot study confirmed the feasibility of engaging YPD in a competition to design and test apps to enhance preparation for clinic appointments. A range of needs were identified in the apps that were designed and some of our preconceptions about likely app functions were challenged. This study strongly supports the idea that YPD should be involved in designing apps for use by YPD, but it may be more appropriate for the primary role of the patients to be to advise on design rather than implementation. It will be particularly important to determine whether competitive app design and evaluation could engage more hard to reach YPD who are at highest risk from poor control of diabetes, as opposed to more self-selected enthusiasts who engaged with this project.

## Acknowledgments

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## Conflicts of Interest

None declared.

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## Abbreviations

**YPD:** young people with diabetes

**NHS:** National Health Service

**UK:** United Kingdom

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Original Paper

# Health Information on the Web and Consumers' Perspectives on Health Professionals' Responses to Information Exchange

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## Abstract

**Background:** Health information technology, which is sometimes referred to as informaticization of medicine, is changing the extent to which patients become competent producers of their own health by enabling them access to health information anytime and anywhere.

**Objective:** This research provides preliminary information on users' perceptions of the extent to which use of the Internet for health information impacts medical encounters. We specifically explored the following questions: (1) To what extent perceptions of positive or negative changes in medical encounters are associated with sociodemographic background of online health information seekers, and how often the Internet information is discussed with providers? (2) To what extent is there an association between perceived changes in medical encounters and frequency of referring to the Internet during medical encounters? (3) To what extent is there an association between sociodemographic background of online health information users and frequency of discussing of the Internet information with providers?

**Methods:** The data for this study was derived from a national sampling of online health and medical information users who participated in the Study of Health and Medical Information in Cyberspace—Survey of User Perceptions (N=710). This study used a nationally representative online research panel of the US adults maintained by the Knowledge Networks. Analysis of variance (ANOVA), chi-square, and *t* tests were performed to examine the data.

**Results:** Although Internet sources allow people the opportunity to gather health or medical information, discussion of this information was not a very common activity. It is noteworthy that half of the sample never or rarely discussed health/medical information obtained from Internet sources with health professionals. Chi-square analyses revealed that discussion of online health information with providers were associated with education, income, and marital status. We also found that discussion of the Internet information mostly promotes better physician-patient interactions. Analyses with post-hoc tests identified that perceived changes in medical encounters were associated with age, education, and income. However, 9.1% (64/703) of our respondents strongly agreed that the interactions with their providers have been strained. *T* test analyses showed that marital status, race, and gender were not significant.

**Conclusions:** Embracing new technologies, and adapting to changing roles and relationships in delivery of medical care are critical to effective delivery of patient-centered care. Health professionals could also guide patients on how to evaluate information and where to access to reliable and accurate information.

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**KEYWORDS**

health communication; Internet; information; patient-physician relationship

## Introduction

Evidence from nationally representative surveys show that nearly half of the US population have sought health-related information on the Internet [1]. A 2010 presidential commission report underscored the importance of health information technology in enabling every consumer access to information they need [1]. Technological reinvention of the way information is created, distributed, and retrieved has led to a thriving movement within the health care system and the medical culture. In fact, the Internet has become a platform for health care information and support to the extent that more than 110 million Americans obtain their health information from Web-based sources [2]. As more patients retrieve health and medical information when and where they need it, they also desire a more active role in their own care and clinical decision making. Previous literature commonly reported that the power dynamics in medical encounters require patients to become well-informed if they prefer to take a proactive approach and be treated with due respect as health care partners [3]. Accordingly, today, in the age of post-information society, it is a common practice that health consumers turn to the Internet first before visiting a physician [4]. Sometimes referred to as the informaticization of medicine, cyber patients surf the virtual library of health and medical information to equip themselves with competencies as they navigate themselves through medical system in offline world [4]. The users of online information access medical knowledge outside of the venue of consulting rooms and they decide on the content and amount of information received. Accordingly, it has been suggested that the Internet provides patients with opportunities to display the modern marker of being a responsible, proactive, and competent patient in the age of information and communication technologies [5].

However, little is known about how obtaining health or medical information from Web-based sources impacts the provider-patient relationship [6]. The Internet is challenging the traditional hierarchical patterns of information provision that used to exist in medical encounters. As patients use the Internet to gather information, the patient-provider dynamic may change in various ways. [7]. Existing reports about the implications of the Internet technology for health care services are conflicting. The Internet is argued to transform the physician-patient interaction by demystifying medical expertise and by redefining patients as eHealth information managers [8]. While some providers may welcome the opportunity to collaborate with proactively informed patients, other providers may feel challenged or their expertise being questioned [9]. A study of oncologists found that health professionals perceive availability of digital health information sources as a positive development, while some embrace this less [10]. Some research found that clinicians react negatively and feel challenged when patients bring information retrieved from the Internet to medical consultations [4]. This is especially the case in instances where Web-based information does not coincide with medical facts and professional opinions [11]. Research also shows that most Internet users do not discuss the Web-based information with their clinicians due to hesitation to over-step the boundary between physician-patient interactions, and concerns about

alienating their physicians by making them feel not trusted [12]. The hierarchical interaction between patients and physicians may diminish the tendency of patients to reveal that they were looking up information from alternative sources, which, in turn may lead to concerns about jeopardizing the quality of health and medical information received.

The current study examined the extent to which gathering health or medical information from the Web resources is perceived as effective medical interactions. This study also examined to what extent perceptions of change in health care interactions are associated with how often Internet information is discussed, and to what extent do people feel that interactions with their health care providers are strained as a result of referring to the information obtained from the Web resources. The impact of patients' sociodemographic backgrounds on these perceptions are also reported.

## Methods

### Data Source and Ethical Approval

The current study used a nationally representative online research panel of US adults maintained by the Knowledge Networks. Knowledge Networks is a non-profit and academic research firm that has recruited the first online research panel representative of the US population. Data was obtained from national sampling of online health and medical information users who participated in the Study of Health and Medical Information in Cyberspace- Survey of User Perceptions. The survey, which consisted of 50 questions, was self-administered and accessible for a designated period of time. Participants were able to complete the survey only once. Knowledge Networks contacted approximately 1000 panelists, of which 710 completed the survey. The inclusion criteria in this study were using the Internet, at least occasionally, to look for health-related information and being at least 18 years of age.

The survey asked the respondents to report whether and to what extent they (1) utilize the Internet to obtain health related information, (2) evaluate the credibility and quality of the Internet information, (3) take action to manage their health based on the Internet obtained information, and (4) perceive encounters with providers are affected by seeking health or medical information on the Internet themselves. Each item was measured on a 5-point Likert scale ranging from 1, never/strongly disagree/not at all to 5, always/strongly agree/very much. Before launching the survey, the items were first pilot tested (n=10). Ethics approval was obtained during the recruitment process before the respondents joined the Knowledge Networks panel. Approval of the Institutional Review Board of the University of Maryland, Baltimore County was also obtained.

### Measures

Demographic and socioeconomic covariates included race/ethnicity, education, income, gender, age, race, and marital status. Age was grouped into four groups: (1) 18-29, (2) 30-44, (3) 45-59, and (4) 60 and older. Gender was coded as (0) male and (1) female. Response categories for race/ethnicity, and marital status were collapsed to account for small cell sizes and were measured as dichotomous variables. Race/ethnicity was

measured as (0) Caucasian and (1) minority. Marital status was measured as (0) nonmarried/nonpartnered and (1) married/partnered. Education was coded as (1) high school or less, (2) some college or associate degree, (3) college degree, and (4) post-graduate degree. Annual family income was categorized into four groups: (1) \$29,999 or less, (2) \$30,000-\$59,999, (3) \$60,000-\$99,999, and (4) \$100,000 and above.

Frequency of seeking health or medical information from the Internet was assessed with a single question: "How often do you seek health or medical information on the Internet?" The response options ranged from (1) never to (5) always. Frequency of discussing online information with health providers was also assessed with a single question: "How often do you discuss the information you obtain from the Internet with a health care provider?" The response options ranged from (1) never to (5) always.

Perceived changes in interactions with health care providers were assessed with 4 items which asked the respondents to indicate the extent to which they agreed with the following statements: (1) "I receive more attention to my questions from health care providers as a result of gathering health or medical information from the Internet," (2) "I receive more information to my satisfaction from health care providers as a result of gathering health or medical information from the Internet," (3) "Interactions of health care providers with me have become more respectful as a result of gathering health or medical information from the Internet," and (4) "interactions with health care providers have become strained as a result of bringing in health or medical information from the Internet to the appointments." The response options ranged from (1) strongly disagree to (5) strongly agree. The last item was reverse coded to be consistent with the other items.

An estimation of the factor structure of these four items using rotated solution with the Varimax method and the Scree plot suggested a two-factor solution. Internal consistency reliability estimate also showed that dropping the last item from the composite scale would increase Cronbach alpha from .59 to .87. Thus, an index score for perceived positive changes in health care interactions was calculated by taking the average of the standardized scores on only the first three items. The minimum score was 1 and the maximum score was 5 with higher scores indicating a greater perceived positive changes. The last item was analyzed separately as a single item of perceived negative change in health care interactions. The response options ranged from (1) strongly disagree to (5) strongly agree with higher scores indicating higher levels of perceived strain.

### Statistical Analysis

Chi-square analysis, *t* test, and analysis of variance (ANOVA) were performed to examine whether significant associations exist between sociodemographic factors, discussion of Web-based information with health providers, and perceived impact of gathering information from Web resources on medical encounters. Data were analyzed using IBM SPSS Statistics version 21.

## Results

The survey sample included adults who ranged in age from 18 to 93 with a mean of 48.82. There were 15.2% (108/710) of respondents younger than 29 years of age and 27.3% (194/710) older than 60 years of age. Just over half of the sample were women (53.7%, 381/710). The majority of the sample was Caucasian (76.5%, 543/710) and married or partnered (67.8%, 481/710). College graduates and those with post-graduate degrees comprised 37.3% (265/710) of the sample while a similar percentage of the sample had high school or less education (33.4%, 237/710). Over half of the sample (57.0%, 405/710) reported an annual household income of at least \$60,000 USD. We found that while 12.4% (88/710) reported frequently seeking health related information on the Internet, one-third reported rarely (32.4%, 230/710). Half of the sample indicated never or rarely discussing the Internet information with health providers (50.0%, 351/702) while 12.6% (89/702) reported frequently. The correlation between frequency of seeking health/medical information on the Internet and frequency of discussing it with providers is significant ( $r=.33$ ,  $P<.001$ ). Chi-square analyses revealed a few significant differences associated with discussion of Internet-based information with health care providers. Higher percentages of individuals with college or more education ( $\chi^2=26.78$ ,  $P=.001$ ), those from upper income brackets ( $\chi^2=13.97$ ,  $P=.001$ ), and those who were married/partnered individuals ( $\chi^2=21.80$ ,  $P=.001$ ) engaged in more frequent discussions of Internet information. Approximately half of those who frequently discussed the Internet information with providers had a college degree or more (47%, 42/89) compared to one-fifth (20%, 18/89) who reported a high school diploma or less. Regarding income, respondents who discussed the Internet information frequently, only 6% (5/89) earned less than \$30,000 USD while 67% (60/89) reported earning \$60,000 USD or more. Chi-square analyses revealed that age, race/ethnicity, gender, and marital status were not significantly associated with discussing the Internet information.

As for perceived changes in medical encounters, one-third (31.3%, 220/702) strongly agreed to the item "I receive more attention to my questions" and nearly over one-third (35.9%, 253/704) indicated strong agreement to "I receive more information to my satisfaction". In response to the statement "interactions of health care providers have become more respectful", while 16.4% (115/702) reported a strong agreement, nearly one-quarter (23.8%, 167/702) reported disagreement indicating no such positive change. On the item measuring perceived strain, 9.1% (64/703) reported strong agreement, while almost half of the sample (48.8%, 343/702) reported disagreement. The composite scale of perceived positive changes showed an overwhelming majority (74.1%, 526/710) reported positive changes ranging from somewhat agreeing (61.8%, 439/710) to strongly agreeing (12.3%, 87/710). However, 25.9% (184/710) reported no such changes in health care interactions. Chi-square tests also identified several variables that were associated with frequency of discussing information obtained from the Internet with perceived changes in health care interactions. Nearly 63% (56/89) of those who frequently

discussed information with professionals reported strong agreement to the item “receiving more attention to their questions from health providers” while the percentage for those who engaged in rare discussions of online information was 17.6% (61/346). Similarly, while 63% (56/89) of those who engaged in frequent discussions strongly agreed that they received more information to their satisfaction. However, the percentage was 21.0% (73/348) for those who rarely engaged in such discussions. A higher percentage of people who reported frequent discussions also strongly agreed that there was an increased respect in health care interactions (35%, 31/89) compared to those who did not (8.6%, 30/347). Comparison of discussers to non-discussers showed that nearly 34% (30/89) of frequent discussers agreed strongly to positive changes on the summated scale compared to nearly 5% (19/348) of non-discussers. Lastly, almost 9% (30/348) of the respondents who rarely discussed Web information reported strong agreement to strained health care interactions. In contrast, nearly twice that percentage was reported by those who frequently

broached up the topic of information obtained from the Internet (17%, 15/88). Detailed percentages, chi-square values, and corresponding significance levels are shown in [Table 1](#).

ANOVA analyses with post-hoc tests also identified several sociodemographic variables that were significantly associated with perceived changes in medical encounters. These factors are age, education, and income. Respondents older than 60 years of age reported less perceived strain in medical encounters than those between the ages of 18-29 (mean 2.40 vs mean 2.66,  $P=.033$ ). Respondents with “some college or less” education perceived an increase in respect as a result of gathering information from the Internet ( $M=3.05$  vs  $M=2.81$ ,  $P=.010$ ). There is also a marginally significant association between higher income and receiving more information to satisfaction (mean 3.26 vs mean 3.03,  $P=.058$ ). *T* test analyses showed that marital status, race, and gender were not significant correlates of perceived changes in medical encounters. ANOVA and *t* test results are shown in [Table 2](#) below.



**Table 1.** Covariates stratified by discussing Internet information with health care providers.

Covariates	Full sample characteristics n (%)	Never/Rarely n (%)	Sometimes n (%)	Mostly/Always n (%)	$\chi^2$ (df)	P
<b>Age, mean (SD)</b>	48.82 (16.43)	49.98 (10.91)	48.88 (15.65)	46.97 (15.19)	5.637 (6)	.465
18-29	100 (15.2)	57 (16.2)	39 (14.9)	11 (12.4)		
30-44	175 (24.6)	86 (24.5)	59 (22.5)	28 (31.5)		
45-59	233 (32.8)	106 (30.2)	96 (36.6)	28 (31.5)		
60 and older	194 (27.3)	102 (29.1)	68 (26.0)	22 (24.7)		
<b>Gender</b>					5.115 (2)	.077
Female	381 (53.7)	176 (50.1)	145 (55.3)	56 (62.9)		
Male	329 (46.3)	175 (49.9)	117 (44.7)	33 (37.1)		
<b>Education, mean (SD)</b>	2.97 (0.96)	2.79 (0.97)	3.12 (0.93)	3.24 (0.85)	26.943 (6)	.00
High school or less	237 (33.4)	143 (40.7)	72 (27.5)	18 (20.2)		
Some college	208 (29.3)	105 (29.9)	72 (27.5)	29 (32.6)		
College degree	153 (21.5)	61 (17.4)	69 (26.3)	22 (24.7)		
Post graduate degree	112 (15.8)	42 (12.0)	49 (18.7)	20 (22.5)		
<b>Income, mean (SD)</b>	2.70 (1.07)	2.60 (1.11)	2.75 (1.07)	2.94 (0.90)	13.974 (6)	.030
\$29,999 or less	122 (17.2)	74 (21.1)	41 (15.6)	5 (5.6)		
\$30,000-\$59,999	183 (25.8)	90 (25.6)	67 (25.6)	24 (27.0)		
\$60,000-\$99,999	191 (26.9)	87 (24.8)	70 (26.7)	31 (34.8)		
\$100,000 or more	214 (30.1)	100 (28.5)	84 (32.1)	29 (32.6)		
<b>Marital status</b>					21.80 (10)	.001
Married	481 (67.8)	208 (59.3)	161 (61.5)	53 (59.6)		
Non-married	229 (32.3)	143 (40.7)	101 (38.5)	36 (40.4)		
<b>Race/Ethnicity</b>					1.126 (2)	.569
White	543 (76.5)	265 (75.5)	206 (78.6)	66 (74.2)		
Non-White	167 (23.6)	86 (24.5)	56 (21.4)	23 (25.8)		
<b>Receiving more attention to questions, mean (SD)</b>	3.12 (0.83)	2.86 (0.79)	3.28 (0.72)	3.64 (0.89)	90.041 (4)	.001
Disagree	132 (18.8)	94 (27.2)	28 (10.7)	9 (10.1)		
Somewhat agree	350 (49.9)	191 (55.2)	134 (51.3)	24 (27.0)		
Agree	220 (31.3)	61 (17.6)	99 (37.9)	56 (62.9)		
<b>Receive more information, mean (SD)</b>	3.21 (0.81)	2.93 (0.78)	3.41 (0.67)	3.66 (0.85)	90.384 (4)	.001
Disagree	109 (15.5)	83 (23.9)	17 (6.5)	8 (9.0)		
Somewhat agree	342 (48.6)	192 (55.2)	123 (47.1)	25 (28.1)		
Agree	253 (35.9)	73 (21.0)	121 (46.4)	56 (62.9)		
<b>Receive more respect, mean (SD)</b>	2.91 (0.78)	2.73 (0.72)	3.04 (0.68)	3.28 (0.82)	54.651 (4)	.001
Disagree	167 (23.8)	111 (32.0)	43 (16.5)	12 (13.5)		
Somewhat agree	420 (59.8)	206 (59.4)	164 (63.1)	46 (51.7)		
Agree	115 (16.4)	30 (8.6)	53 (20.4)	31 (34.8)		

Covariates	Full sample characteristics n (%)	Never/Rarely n (%)	Sometimes n (%)	Mostly/Always n (%)	$\chi^2$ (df)	<i>P</i>
<b>Positive changes in health care interactions, mean (SD)</b>	3.08 (0.71)	1.68 (0.57)	3.24 (0.58)	3.53(0.76)	86.924 (4)	.001
Disagree	184 (25.9)	130 (37.4)	42 (16.0)	10 (11.2)		
Somewhat agree	439 (61.8)	199 (57.2)	184 (70.2)	49 (55.1)		
Agree	87 (12.3)	19 (5.5)	36 (13.7)	30 (33.7)		
<b>Interactions strained, mean (SD)</b>	2.50 (0.82)	2.55 (0.80)	2.45 (0.75)	2.49 (1.03)	19.034 (4)	.001
Disagree	343 (48.8)	152 (43.7)	139 (53.5)	49 (55.7)		
Somewhat agree	296 (42.1)	166 (47.7)	103 (39.6)	24 (27.3)		
Agree	64 (9.1)	30 (8.6)	18 (6.9)	15 (17.0)		

**Table 2.** Covariates stratified by perceived impact of discussing health/medical information from the Internet on medical encounters.

Covariates	More attention	More information	More respect	Positive changes in health care	Interactions strained
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
<b>Age</b>					
18-29	3.03 (0.93)	3.08 (0.96)	2.86 (0.89)	2.91 (0.77)	2.66 (0.96)
30-44	3.13 (0.79)	3.22 (0.73)	2.92 (0.73)	2.96 (0.56)	2.57 (0.81)
45-59	3.14 (0.80)	3.21 (0.76)	2.92 (0.72)	2.94 (0.57)	2.47 (0.77)
60 and older	3.13 (0.83)	3.26 (0.83)	2.93 (0.71)	2.92 (0.56)	2.40 (0.77)
<i>F</i> test	$F_{3,701}=0.509$	$F_{3,700}=1.096$	$F_{3,701}=0.235$	$F_{3,701}=0.202$	$F_{3,699}=2.920$
<i>P</i> value	.676	.350	.872	.895	.033
<b>Gender</b>					
Female	3.09 (0.86)	3.22 (0.78)	2.89 (0.77)	2.91 (0.62)	2.48 (0.81)
Male	3.15 (0.80)	3.20 (0.83)	2.94 (0.72)	2.96 (0.58)	2.54 (0.82)
<i>t</i> <sub>df</sub> test	$t_{700} = 0.986$	$t_{736} = 0.337$	$t_{700} = 0.864$	$t_{703} = 1.097$	$t_{701} = 1.012$
<i>P</i> value	.324	.736	.388	.273	.312
<b>Race/Ethnicity</b>					
White	3.13 (0.81)	3.21 (0.79)	2.90 (0.72)	2.93 (0.58)	2.48 (0.80)
Non-White	3.09 (0.89)	3.19 (0.86)	2.96 (0.82)	2.96 (0.68)	2.59 (0.86)
<i>t</i> <sub>df</sub> test	$t_{700} = 0.471$	$t_{702} = 0.333$	$t_{700} = 0.949$	$t_{703} = 0.570$	$t_{701} = 1.445$
<i>P</i> value	.637	.740	.343	.569	.149
<b>Education</b>					
High school or less	3.09 (0.86)	3.14 (0.86)	2.91 (0.77)	2.93 (0.65)	2.56 (0.85)
Some college	3.17 (0.83)	3.27 (0.80)	3.05 (0.76)	3.01 (0.61)	2.55 (0.81)
College degree	3.08 (0.77)	3.18 (0.74)	2.81 (0.70)	2.89 (0.55)	2.47 (0.78)
Post graduate	3.11 (0.86)	3.27 (0.78)	2.82 (0.71)	2.94 (0.55)	2.36 (0.76)
<i>F</i> test	$F_{3,698}=4.66$	$F_{3,700}=1.154$	$F_{3,698}=3.829$	$F_{3,701}=1.647$	$F_{3,699}=1.921$
<i>P</i> value	.706	.326	.010	.177	.125
<b>Income</b>					
\$29,999 or less	2.98 (0.85)	3.03 (0.86)	2.93 (0.80)	2.85 (0.64)	2.46 (0.82)
\$30,000-\$59,999	3.15 (0.84)	3.23 (0.82)	2.93 (0.77)	2.97 (0.61)	2.58 (0.80)
\$60,000-\$99,999	3.12 (0.81)	3.26 (0.77)	2.89 (0.75)	2.94 (0.57)	2.50 (0.83)
\$100,000 or above	3.17 (0.83)	3.25 (0.78)	2.92 (0.70)	2.95 (0.59)	2.47 (0.81)
<i>F</i> test	$F_{3,698} = 1.582$	$F_{3,700}=2.509$	$F_{3,698}=0.126$	$F_{3,701}=1.186$	$F_{3,699} 0.851$
<i>P</i> value	.192	.058	.945	.314	.466
<b>Marital status</b>					
Married	3.13 (0.79)	3.23 (0.75)	2.89 (0.71)	2.93 (0.55)	2.48 (0.78)
Non-married	3.10 (0.89)	3.18 (0.89)	2.95 (0.80)	2.94 (0.67)	2.54 (0.86)
<i>t</i> <sub>df</sub> test	$t_{700} = 0.392$	$t_{702} = 0.836$	$t_{700} = 0.914$	$t_{701} = 0.181$	$t_{701} = 0.814$
<i>P</i> value	.702	.404	.361	.856	.416

## Discussion

### Principal Findings

This study examined sociodemographic correlates of discussing Internet-based information with health care providers. We also examined whether respondents' reports of perceived changes in medical encounters were associated with their sociodemographic background characteristics and how often they engaged in discussion of information from Web sources.

First, a striking finding from this research is that an overwhelming majority (87.6%, 622/710) reported sometimes or rarely searching for health or medical information on the Internet. This might be because most participants were healthy and did not feel the need to search for such information. In fact, a survey by the Pew Research Center's Internet & American Life Project showed 80% of American adults reported their health as excellent or good and do not frequently access health information [13]. Alternatively, as data from the Health Information National Trends Survey (HINTS) indicate that despite wide availability of online health or medical information, the public trust in Internet-based information has decreased and the majority of Americans prefer health care professionals as more trusted source of information [14]. This interpretation is also consistent with the Pew research results that nearly 90% of all adults turn to a health professional when they need information or assistance in dealing with health or medical issue. The Pew report states "American adults continue to turn to traditional sources of health information, even as many of them deepen their engagement with the online world" [15].

In corroboration of the HINTS results, this study also revealed differences in use of the Internet health information by sociodemographic characteristics. Specifically, use of the Internet for health purposes was found to be more common among females, Caucasians, and younger people. The fact that half of the respondents were women is consistent with other studies showing closing gender gap in usage of the Internet technology [2]. However, the fact that the majority of the respondents were Caucasian and in higher income brackets is suggestive of persistent digital divide based on racial/ethnic and economic inequalities. Nearly one-third of participants who reported searching the Internet for health information were older adults. This might be indicative of growing popularity of the Internet among cohorts of older adults and narrowing of the generational digital divide.

It is noteworthy that half of the sample never or rarely discussed health/medical information obtained from the Internet with their health care providers. Some of the sociodemographic variables, such as gender and race/ethnicity, that are traditionally associated with online health-seeking behavior were not found to be significantly associated with frequency of discussing Web information with health professionals. Similar to the results of this survey, the Pew survey showed that over 60% of people who look up health information on the Internet reported never or sometimes discussing information they found on the Internet with health care professionals [13]. This could be due to structural limitations of the health care system limiting time that could be set aside for discussion of information from outside

sources, or because of patient concerns for not to be perceived as challenging the authority and expertise of their care providers [16]. Although Internet sources allow people the opportunity to gather health or medical information, discussion of it was not found to be a very common activity.

One caveat noted in the literature is that those with poor health or sicker patients were more likely to talk with a clinician about what they found on the Internet [17]. The Pew Research Center's Internet & American Life Project reported that those who reported worse health status and people living with chronic conditions used Internet health information more frequently when they have access to the Internet and also more frequently discussed Internet information with health care providers [13]. Another research also reported that less than one-third of people who indicated a good health status discussed the Internet health information with their health care provider [16,17].

The results suggest that higher education and income seem to be enabling factors for engagement in discussion of online health information with providers as they were found to be significant in chi-square analyses. This is mostly due to probability that people with higher education and income use the Internet more often, which is also consistent with previous research that health information seeking was more common among higher education and income groups [18,19]. Being in a relationship with a significant other also seems to be another enabling factor. In fact, research has shown that having a partner encourages one to become more assertive and proactive in asking questions to a provider during medical appointments [20].

Regarding the impact of bringing in information from Web sources to appointments and discussing it with providers, we found that it mostly promotes better medical encounters rather than straining it. An overwhelming majority perceived their questions resulted in more attention from their providers and more information provided to their satisfaction. Sense of being more respected as a health care partner is also reported. This could be due to health providers' appreciation of their patients' efforts to become more proactive in maintaining and/or regaining their health, and possibly perceiving their patients as informed partners rather than passive and helpless consumers of their services [21].

### Limitations

We should interpret these results with caution that almost half of the sample reported some strain due to bringing in the Internet information to their appointments. Nine percent of our respondents strongly agreed that the interactions with their providers had been strained. It is noteworthy that older adults reported less strain compared to adults in 18-29 age group. This might be related to health providers' appreciation of use of the Internet by older adults, an age group less expected to use technology in an effort to be in charge of their health and well-being. In contrast, younger adults bringing in information obtained from the Internet might be perceived as challenging the "informational" authority and expertise of health care providers with their technological gadgets or toys. This is an interesting area of further inquiry in order to better understand the age or cohort factor that our results suggested. Another interesting result out of this study is reports of perceived increase



in respect by those with “some college” education. This could possibly be due to feeling more confident in interacting with health professionals as a result of gathering information or a real change in attitudes of health providers in interacting with patients who might be less expected to gather information in order to discuss it during medical appointments.

Even though inquiring into health status of the study participants in the current study would have enabled us to analyze the synergy between self-reported health status, frequency of using the Internet for health information, and discussion of it with providers in-depth, the funding limitations constrained the number of questions that could be explored in the survey. Another area of limitation of the current study is that those with chronic health issues or serious diseases may use the Internet in more targeted ways than those who browse the Internet for general health purposes, which in turn, may affect medical encounters differently and provoke differential reactions from providers. The Pew Internet Health Tracking Survey results indicate that the diagnosis of a chronic condition makes a difference in the extent to which people with serious health concerns conduct targeted and specific online research [13,15]. The HINTS also found that there are differences in use of the Internet for health purposes by those who are more sick or have a serious disease compared to those who reported no conditions or being healthier. Even though those who are in poor health may be less likely to be online, they tend to gather more in-depth information when online more frequently [13]. Other research also reported that those with serious chronic illnesses consult the Internet resources for specific information, such as on their doctors' expertise, a certain medical treatment, or medications [17].

Among the other limitations of the current study is that we could not explore health insurance status, and rate of use of health care services by the study participants. Moreover, the survey

could not inquire about the type of Internet sites the respondents were visiting. Future research that would directly observe how patient-provider interactions are affected by patients' use of the Internet health information resources will help us better understand the various dynamics involved. We also need to understand whether online information results in patient requests such as for additional tests or procedures. Due to a limited set of questions used in the current survey, we were also unable to probe into potential causes of perceived strain and perceived changes in medical encounters. Additional research is also needed to examine whether and how information obtained from the Web sources is integrated into self-care.

### Future Studies

Future papers out of our survey data will analyze questions that inquired about patient non-adherence and non-compliance as a result of using the Internet health or medical information, trust in Internet provided health or medical information, and self-reported ability to evaluate quality and credibility of the Internet health or medical information.

### Conclusions

The Internet empowers patients with broader and richer sources of information if there is a timely and satisfactory health information exchange [22]. In today's complicated health care context, patients explore their options in order to participate in management of their care [23]. They desire up-to-date information to improve the quality and efficiency of services they receive [24]. Embracing new technologies, and adapting to changing roles and relationships in delivery of medical care are critical to effective delivery of patient-centered care [1]. Health professionals could also help patients get quality health information by guiding patients on how to evaluate information and where to access reliable and accurate information online [25].

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### Conflicts of Interest

None declared.

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