

PATIENT PREFERENCES FOR CANCER CARE MHEALTH APPS:  
A DISCRETE CHOICE EXPERIMENT

by

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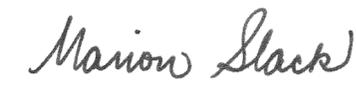
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## **Abstract**

**Background:** It has been argued that mHealth apps could bridge the gap between direct provision of patient care services and patient self-management of oral oncolytic therapies. The ability of non-regulated one-way communication apps can be studied for their impact on patient disease self-management decisions. The purpose of this project was to explore whether discrete choice methods, such as a choice-based conjoint exercise, could be applied to discern patient preferences for the features of mHealth cancer apps for disease self-management. While the major portions of this work were hypothesis generating, we did set the following hypothesis:

*There is no difference in the relevance of attributes and levels for features of cancer self-management mHealth apps with respect to patient preferences.*

**Methods:** As the purpose of this study was to explore the depth and breadth of research on mHealth app features for cancer self-management, a scoping review methodology was adopted for this study. Four databases were used for this review: PubMed/MEDLINE, EMBASE, CINAHL, and PsycINFO. Citation and reference searches and a gray literature search were conducted. Data were extracted from articles including cancer type, mHealth app features, and patient preferences. The features listed for each app were compared, highlighting similarities across platforms as well as features unique to each app. The 40 app features identified in the scoping literature review were collated into groups according to their function. This resulted in nine groups and these groups formed the basis of questions for the expert opinion survey. Participants were asked to endorse each feature deemed useful for patients in cancer self-management. After each question respondents were asked to contribute additional app features

related to that group which might also be useful to patients. The data were analyzed to determine the attributes with the highest relevance for mHealth apps for cancer patients according to the subject matter experts (as measured by lowest composite score when a rating of 9 out of 9 is the most relevant). A survey containing a choice-based conjoint exercise was utilized to reveal patient preferences for the features we previously identified in mHealth apps in the literature. The choice exercise consisted of nine choice tasks in which respondents compared the features of hypothetical mHealth apps for cancer self-management. This analysis utilized a latent class multinomial logit model to identify different segments (groups) of respondents based on response patterns.

**Results:** In total, seven studies published from 2017 to 2021 were included for analysis.

Additionally, apps were developed to address the needs of a heterogeneous patient population; some address the needs of a single cancer indication or treatment, and others provide support across the spectrum of cancer diagnoses. Likewise, the number of features per app varied from two to eleven with a median of four – with the most reported feature being a symptom tracker. Lastly, several studies reported patient acceptability or preference data for the app and/or the features with acceptability (assessed through survey or interviews) most frequently reported.

However, these apps and features are often developed with little input from patients.

Additionally, there is little information regarding patient preferences for the features of existing apps. A total of nine experts responded to the survey. Only two questions included features that were not endorsed by seven or more participants. Each category of features was accompanied by an open-ended question allowing the respondents to introduce features not identified in the literature. The patient survey showed contrasts in respondent preferences depending on question format. In addition, latent class analysis revealed evidence for a two-group model. In the rating

scale question in the introduction of the survey, “Calendar” was the attribute which received the highest percentage of respondents reporting that the attribute was “Very useful” (n = 80, 72.7%) while “Symptom tracker” was rated lowest (tied with “Education”), as only 70 respondents (63.6%) considered this attribute “Very useful”. However, in the LCA both groups 1 and 2 indicated the highest preference for the “Symptom tracker” attribute (in Group 1 this accounted for 30.4% of total attribute importances and in Group 2 it accounted for 31.4%). The latent class analysis revealed only one statistically significant difference between Groups 1 and 2.

Respondents who identified as Hispanic, Latino, or of Spanish origin (n = 13) were all in Group 1.

**Conclusions:** The objectives of this formative research were to demonstrate whether discrete choice methods were fit-for-purpose in determining patient preferences for mHealth app features through expert opinion and patient surveys. The choice-based conjoint patient survey revealed there are differences between patient groups for preferred app features. Based on these outcomes, we are able to reject the null hypothesis that there is no difference in patient preferences for features of mHealth apps for cancer self-management. There are findings from this research that warrant further exploration. When asked with a rating question how useful app features would be, both experts and patients selected “Calendars and planning” (in the expert survey) or “Calendar” (in the patient survey). This differed from the outcome of the choice-based conjoint exercise in which both groups of patients in the latent class analysis model rated “Symptom tracker” as the attribute of highest importance. More research is needed to define methodologies best fit for purpose in understanding patient preferences.

## **Chapter 1: INTRODUCTION**

### **mHealth**

Mobile health, or mHealth, is a recent development in the health care industry. The World Health Organization defines mHealth as “the use of mobile and wireless technologies to support the achievement of health objectives” (World Health Organization, 2011). Additionally, the National Institutes of Health defines mHealth as “the use of mobile and wireless devices (cell phones, tablets, etc.) to improve health outcomes, health care services, and health research” (What is mHealth, 2020). mHealth can be further specified as a branch of telehealth that is driven by software applications for consumer electronic devices and typically does not involve interaction with a clinician (What is mHealth, 2020). A key differentiation between mHealth and telehealth is that the former is primarily utilized for self-care using consumer electronics and the latter encompasses all modern technologies (What is mHealth, 2020). The other major distinction is that telehealth typically entails clinician-clinician or clinician-patient interaction whereas mHealth typically entails patients collecting data about themselves (What is mHealth, 2020).

#### *mHealth modalities*

mHealth may involve the use of software applications (apps) for consumer electronic devices such as smartphones or tablets, the use of a biosensor or other accessory used alone, or a combination of an app with an electronic device (Cleary, 2018). A biosensor is embedded in a wearable device and allows for the real-time capture of data about the consumer’s health status – sometimes entirely passively (Cleary, 2018). Such mHealth innovations present patient-centric

approaches to clinical trial data collection and improved data collection compared to patient self-report diaries (Cleary, 2018).

A common example of mHealth is a weight or exercise tracker app. The functionality of this type of app is limited. Communication is one-way, the user inputs data into the app and the app stores the data. The user can view the stored data to track trends over time. This type of app is easily available for download through a search on the internet or through an app downloading site such as the Apple iOS or Google Play stores. Apps of this type extend to disease prevention, diagnosis, self-management, and survivorship.

Another example of mHealth is a biosensor such a smartwatch. The functionality is also limited as it can store data and transmit data wirelessly to another device but cannot receive incoming communication. The user wears this device to collect data on biological processes (such as heart rate) or physical activity (such as steps taken). This data can be shared with a software application for other consumer electronic devices such as a smartphone or tablet.

The third example is an mHealth app with an electronic patient portal that allows for communication with a clinician. This is the most complex type of app as it allows for two-way communication and the sharing of personally identifying health information. An app of this type would require the most regulatory oversight.

### *Availability of mHealth apps*

With the launch of the Apple iPhone in 2007, apps were introduced to the consumer market (Baxter et al., 2020) According to estimates on the U.S. Food and Drug Administration (FDA) website, there were 325,000 health care apps available for smartphones in 2017 (Digital

Health Center of Excellence, 2020). This equated to an estimated 3.7 billion downloads globally (Pohl, 2016). Furthermore, IQVIA estimated in 2017 that more than 200 mHealth apps were being added to online access points (such as “app stores”) each day (Global Oncology Trends, 2018). Given the growth in the percentage of health-related apps for smartphones it was estimated that 500 million patients would be using such apps by the year 2015 (Wolf et al., 2013).

### *Access to mHealth*

mHealth projects are active across the globe as, increasingly, consumers have access to electronic devices that connect to cellular in internet services. Within the U.S., the Pew Research Center reported that half of adults owned a tablet device in 2019 (Mobile Fact Sheet, 2019). Additionally, 96% of US adults owned a cellphone with 81% owning an internet enabled smartphone in 2019 (Mobile Fact Sheet, 2019). Cancer patients report receiving support from online communities. The virtual spaces allow users to both ask questions and respond to the questions of others (Gupta and Schapira, 2018).

However, to temper the enthusiastic uptake of mHealth apps globally, there is evidence for a consumer trend to turn away from mHealth apps in recent years (Rupp, 2020). According to a survey by the Accenture group, mHealth app use fell from a 2018 high of 63% of people in the US to 50% in 2020. Among the chief concerns with mHealth apps were privacy and data security. In 2018, Philips, developers of the HealthSuite mHealth app issued a consumer alert warning of weak security features that made the app more susceptible to hacking (Wicklund, 2018).

Many in the US still view hospitals and physicians as entities where data was secure (84% and 83% respectively) yet trust for technology companies and the government was much lower (45% and 38%). Therefore, healthcare providers can play an important role in promoting the use of those mHealth apps which can be of greatest benefit to patients and build trust to using apps to manage health conditions. In fact, 55% of those interviewed stated they would be open to more actively managing their health if their physician worked with them on the transition to technology (Rupp, 2020).

#### *Disease areas where mHealth has been applied – a curated selection*

mHealth has already been studied or applied in a surprising variety of disease states, whether for prevention and education or disease state management. Because mHealth can allow for the remote monitoring of conditions (whether through one- or two-way communication channels) it can be used to study and improve medication adherence for AIDS, anxiety, cardiovascular disease, diabetes, post-partum mental health, and tuberculosis (Tack et al., 2018; Devi et al., 2015; Walsh, Saab, and Farb, 2019; Hamine et al., 2015; Pfaeffli Dale et al., 2015; King et al., 2017; Nair et al., 2018). An emerging trend within the field of mHealth is the use of apps for long-term chronic disease medication adherence, such as text reminders to epilepsy patients to take medication or remote monitoring of diabetes patients through medication tracking (Elliot, 2010; Chomutare et al., 2011).

#### *Potential of mHealth apps to aid cancer patients*

Many oncology apps focus on the needs of cancer patients and their caregivers addressing disease management, patient education, side effect reporting and/or survivorship (Lee, 2018). Most apps developed for this purpose are not required to seek approval from the FDA as a medical device (Lee, 2018). This leaves the task of deciphering the differences between apps intended for cancer prevention, cancer screening, patient education, or other functions on patients (Lee, 2018). However, as cancer therapies move increasingly away from intravenous to oral patients are left with a larger degree of disease management than ever before (Lee, 2018). Indeed, in 2017 eight out of fourteen new active oncology treatment substances approved for launch in the U.S. were oral oncolytics (Global Oncology Trends, 2018).

It has been argued that mHealth apps could bridge the gap between direct provision of patient care services and patient self-management of oral oncolytic therapies, however, few of the oncology apps currently available for download are regulated by the FDA as medical devices or have the capacity for two-way communications between clinicians and patients or caregivers (i.e., push-pull data sharing) (Lee, 2018). Unfortunately, to date, there is little to no availability of push-pull communication apps for cancer management outside of a clinical trial. Therefore, the ability of non-regulated one-way communication apps can be studied for their impact on patient disease self-management decisions.

### **Study Purpose**

The purpose of this study is to explore the usefulness of combining qualitative and quantitative methods to elicitation of patient preferences for the features and functions of mHealth apps for cancer self-management. This study will employ discrete choice methodology

to discover the features and functions of mHealth apps for cancer self-management described in the literature, elicit expert opinion of the relevance for the features and functions discovered in the literature review for patients, and pilot test a discrete choice experiment survey among cancer patients and survivors.

The theoretical underpinnings for this study draw largely from the Technology Acceptance Model (TAM) first put forth by Davis (1989). The essence of the TAM lies in the perceived usefulness of a technology to an end user. Figure 1, below, outlines the main components of the TAM.

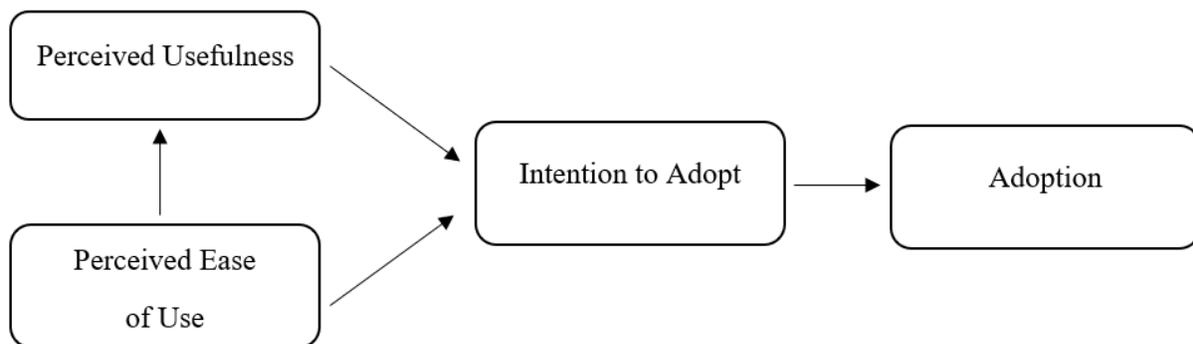


Figure 1. Technology Acceptance Model diagram.

### *Research Objectives*

#### Objective 1

To characterize key features and functions that influence cancer patient preference for mHealth apps using a scoping review of the literature

### Objective 2

To characterize key features and functions that influence cancer patient preference for mHealth apps using subject matter expert opinion collected through a Delphi method survey

### Objective 3

To create a discrete choice survey instrument and to assess validity and reliability in the cancer patient population

### Objective 4

To quantitatively determine cancer patients' preferred app design

### *Hypothesis*

There is no difference in the relevance of attributes and levels for features of cancer self-management mHealth apps with respect to patient preferences.

## **Chapter 2: LITERATURE REVIEW AND THEORETICAL MODEL**

### **Previous research**

#### *Reviews of cancer-focused mHealth apps – features and functionality*

Several reviews have been conducted regarding the number and types of mHealth apps available. In 2013, Bender et al. reviewed 295 cancer-focused mHealth apps developed between 1990 and 2012. Breast cancer apps were most prevalent (47%) followed by general cancer apps (29%) – whereas apps focused on disease self-management accounted for just 4%. Prochaska, Coughlin, and Lyons carried on from this study in 2017. Of the apps available in the Bender et al. study they did not identify a single empirical evaluation of a cancer-focused mHealth app.

Similarly, a non-systematic review cited by Prochaska et al. noted the functionality of apps available in 2015. At that time, 10% had the ability to connect to a device or sensor and 2% could connect with providers. The review noted very few could connect to social networks. (McCarthy, 2015).

In 2014, Mirkovic, Kaufman, and Ruland provided a review design and evaluation processes for mHealth apps supporting cancer self-management. The study revealed 27 design issues (13 for mobile apps and 14 for tablet apps) related to source events (errors, requests for help, participants' concurrent feedback, and moderator observation). Many violations were related to enabling ease of input, screen readability, and glanceability (15 issues), as well as matching between systems and the real world (7 issues) and mapping of system functions and interactions (4 issues).

More recently, Charbonneau et al. (2020) observed that 50% of identified cancer-focused mHealth apps were information only, 20% of apps included features for self-managing disease state, and just 3% of apps included a statement that the content was reviewed by clinicians.

### *Research on patient preferences for cancer-focused mHealth apps*

The evidence base is less robust regarding the collection of patient feedback during cancer-focused mHealth app evaluation and how it is incorporated into app design. Returning to Mirkovic, Kaufman, and Ruland (2014), feedback collected using semi-structured interviews highlighted that patient needs fluctuate depending on the phase of illness or course of treatment. Additionally, a higher level of experience in using mobile technologies facilitated ease of use (Mirkovic, Kaufman, and Ruland, 2014). Furthermore, Kessel, Vogel, and Kessel (2017) used a survey approach to understand patients' technical knowledge, willingness to transfer data to a health care provider, and the desirability of proposed app features. The authors found that age and gender are strong predictors of the features needed for mHealth solutions that meet patient needs. The authors also found that half of oncology patients were willing to share data about disease state management via an app and recommended future mHealth app development should focus on two-way communication between patients and providers. Finally, Harder et al. (2017) utilized the output of patient focus groups to guide the development of an mHealth app for breast cancer surgery recovery. While patients found the app easy to use, further research was needed to establish its clinical utility.

### **Limitations of previous research**

Previous research employed a wide variety of methods to obtain patient end-user feedback (surveys, interviews, and focus groups). However, there is no evidence on the full development process of a Discrete Choice Experiment survey instrument as described in Mathijssen et al., 2018. While the various strategies used to develop a DCE survey instrument are described individually (such as literature review or focus groups), there is no description of the complete development process.

### **Unresolved issues/unanswered questions**

Much previous work has engaged users in the design of mHealth apps yet there is a lack of consensus on how patient preferences should be measured or how they should be incorporated into the app development process. In particular, whether the needs of oncology patients differ in any significant ways from other types of disease self-management that would drive the features and functions available in mHealth apps. While prior work has focused on qualitative methods to elicit patient preferences for mHealth app features, there has been no exploration of the validity or feasibility in using stated preference methodologies.

### **Theoretical model**

Several theories naturally lend themselves to a discussion of consumer choice, in this case between features of mobile health applications which allow for the self-management of a cancer. Several theories underpin preference models: Characteristics Demand Theory, Choice Modeling, and Expected Utility Theory. Together these theories form the basis for Discrete

Choice Experiment methods. In addition, this study draws on the Technology Acceptance Model from the field of information systems, proposed by Davis in 1986 (Davis, 1989).

### *Characteristics Demand Theory*

The Characteristics Demand Theory was put forward by Kelvin Lancaster in 1966. The theory states that consumers derive utility not from the contents of the basket but from the characteristics of the goods in it. In short, there are differences between brands of consumer goods that lead consumers to prefer one over another (taste, shelf-life, performance, etc) (Train, 1986).

### *Choice Modeling*

The theory of Choice Modelling describes the decision-making of an individual through revealed or stated preferences in relation to a particular context. More specifically, discrete choices must be made between options (e.g., A over B, C over A, etc.). Choice modelling is considered the most suitable methodology for eliciting preferences for quality improvements (such as to the features or functionality of an mHealth app) (Centre for International Economics, 2001).

### *Expected Utility Theory*

Expected utility theory can be described as a tool individuals use to make decisions without being fully aware of all possible outcomes (List and Haigh, 2005). This theory

contributes to Discrete Choice methodology in that participants are asked to make a series of decisions in Discrete Choice Experiments in which the outcomes are limited to the levels identified a priori by the researchers.

### *Discrete Choice*

Discrete Choice models predict consumer preferences between limited options. These options are called attributes and levels and describe features or functions of a given product or group of products (such as a class of medications). Market researchers or product developers typically conduct Discrete Choice Experiments to understand consumer preference for pricing and product features (Train, 1986).

### *Technology Acceptance Model*

The Technology Acceptance Model (TAM) is a long standing and well researched theory of individual acceptance of information systems. There have been several adjustments to the model over the past twenty-four years, yet it remains the most widely applied model in the field of information systems. Information systems (IS) are typically thought of as applying to business productivity. For the purposes of this study the theory was applied to individual consumer choice based on the elements of the model being a useful way to think about what might drive patients to select a particular mobile software application as their tool for managing medication adherence and systems of disease. The elements of the TAM are perceived usefulness, perceived ease of use, behavioral intention, and behavior. A meta-analysis of IS research on the TAM has shown that perceived usefulness is the most powerful variable in the model with a particularly

strong determinant of behavioral intention. Seventy-four studies supported the significant relationship between these two variables. In contrast, perceived ease of use is a weaker predictor of behavioral intention. Only 58 studies demonstrated that consumer perceived ease of use influenced behavioral intention. In short, if consumers perceive the technology will be useful in accomplishing their goal they will use it, even if it is cumbersome. Additionally, consumers will be less likely to use a technology they perceive to be easy to use if it will not aid them in accomplishing their goals. In this way, the TAM is a useful theoretical orientation for this study as the variables of perceived usefulness, perceived ease of use, behavioral intention, and behavior can be explored through the means of a discrete choice instrument (Lee, Kozar, and Larsen, 2003).

### **Overview of study design and methods**

A discrete choice methodology is particularly appropriate for studying patient preferences for the features and functionalities of an mHealth app. With the additional application of the Technology Assessment Model (Davis, 1989), patient preferences can be further understood with regard to patient intent to adopt mHealth as one of their cancer self-management strategies.

The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) has established a best-practice methodology for conducting conjoint analysis, which includes discrete choice experiments (Bridges et al., 2011). While ISPOR considers discrete choice experiments to be a subset of conjoint analysis, there has been some debate among experts in the field as to the accuracy of this designation (Louviere, Flynn, and Carson, 2010). However, as a leader in research standards-setting for pharmacoeconomic and outcomes research, ISPOR

guidelines are a suitable starting point for literature critique. Of note, the ISPOR checklist contains ten items, each with three sub-items, for a total of thirty criteria for analysis. The checklist covers all points of a discrete choice experiment from instrument development through full-scale implementation and statistical analysis.

In 2018, Mathijssen et al. argued there are four components to the development of a discrete choice instrument: literature review, expert opinion, patient focus groups or interviews, and pilot testing. In addition, the authors called for greater transparency in the development of discrete choice instruments and suggested best practice methodology (Mathijssen et al., 2018). More recently, an ISPOR webinar was launched titled, “Why and How to Use Qualitative Methods in Conjunction with Discrete Choice Experiments in Healthcare” which outlined the importance of including qualitative methods such as focus groups and patient cognitive debriefing in the development of survey instruments for DCE (Hollin and Vass, 2020). Additionally, careful consideration should be taken to establish the appropriate number of attribute levels so that choice tasks are not so complex as to overwhelm study participants (Louviere, Pihlens, and Carson; 2010).

#### *Key steps to developing a discrete choice survey instrument*

The first step in developing a discrete choice survey instrument is the identification of potential patient preferences through a review of the literature (Mathijssen et al., 2018). This literature review can be systematic or scoping in nature, depending on the subject under study and the amount of data likely to be found in this area. Arksey and O’Malley authored the seminal publication regarding scoping review methodology in 2005. More recently, the Preferred

Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) together with the Joanna Briggs Institute modernized scoping review methods and authored the PRISMA Scoping Review guidelines (Tricco, 2018). Scoping review methods are particularly well-suited to an exploration of patient preferences for mHealth apps as much information regarding this newly developed and niche field may lie within gray literature and trade publications.

The next step in the development of a discrete choice survey instrument should be the assessment of potential attributes and levels identified in the literature through expert review (Mathijssen, 2018). Seeking expert opinion can take a number of forms including one-to-one interviews delivered in-person or over the phone, focus groups, or surveys. The methodology may allow for experts to include attributes and levels felt to be relevant to the subject under study, in which case utilizing a Delphi Method strategy will capture feedback on all attributes and levels added by experts (Dalkey and Helmer, 1963).

The third step in the development of a discrete choice survey instrument involves patient feedback on potential attributes and levels through focus groups or read-aloud/think-aloud semi-structured interviews (Mathijssen, 2018; Pearce, 2020).

The final step in the development process should involve a pilot test of the discrete choice survey instrument (Mathijssen, 2018). Additionally, the survey instrument can be assessed for validity and reliability (or suitability for purpose) through discrete choice analytical software such as Sawtooth Choice Analysis Software (Provo, UT).

## **Chapter 3: SCOPING LITERATURE REVIEW**

### **Introduction**

Cancer is increasingly being treated as a chronic disease rather than an acute one-time illness (Hirsch, 2018; Armstrong, 2002; Afrasiabi et al., 2020). Some cancers, such as chronic leukemia and ovarian cancer can be managed, sometimes described as “controlled”, in a state where the cancer does not grow but is also not cured for months or years. Additionally, oral anti-cancer therapies, as opposed to intravenous chemotherapy, are now available for an increasing number of cancer indications (Gillespie, 2020; Sawicki et al., 2016). These oral treatments are typically self-administered by the patient outside of the clinical setting, presenting challenges (such as symptom and side-effect management) for patients, their families, and their caregivers (Marshall and Cairns, 2019; Ruddy, Mayer, and Partridge, 2009; Given and Given, 2016).

A 2015 literature review found that healthcare systems and patients were meeting the challenges of managing self-administered medicines by using mobile health software applications (mHealth apps) (Nasi, Cucciniello, and Guerrazzi, 2015). mHealth apps for use on mobile devices (such as smartphones or tablets) are designed to help patients with medication adherence, symptom tracking and disease management (Osborn et al., 2020). A 2021 analysis found 794 oncology-specific English language mHealth apps (Upadhyay, Landman, and Hassett, 2021). Nasi, Cucciniello, and Guerrazzi (2015) found that patients with cancer mainly used mHealth apps for self-management activities. Self-management can be described as a patient’s ability to deal with all aspects of a chronic illness, such as symptoms, treatment(s), and physical, social, and lifestyle changes.

A wide variety of mHealth apps are available for cancer care (prevention, screening, diagnosis, treatment management, and survivorship) (Prochaska, Coughlin, and Lyons, 2017; Davis and Oakley-Girvan, 2015). While some apps allow for two-way communication with healthcare professionals and/or caregivers, others are solely for the patient to track data such as disease symptoms or physical activity (Prochaska, Coughlin, and Lyons, 2017; Pandey et al., 2013). A literature review conducted by Bender et al. (2013) cataloged mHealth apps providing tools for the self-management of cancer and sorted their features into three groups: appointment tools (for example, reminders for visits with healthcare team), self-monitoring functionality (such as, patient tracking of disease symptoms and medication side-effects), and communication capability (for example, text messaging with a member of the healthcare team). In 2012, a study by Pandey et al. (2013) showed that fewer than half of cancer care apps were free of cost (42.8%) while the remainder charged fees for downloading. With such heterogeneity in cost and function, it is imperative to understand what features are preferred by patients to best meet their cancer care needs.

Several previous literature reviews have been conducted regarding mHealth apps for cancer. Bender et al. (2013) conducted a systematic review and content analysis of apps for the prevention, detection, and management of cancer. Nasi et al. (2015) conducted a literature review regarding the role and use of mHealth technologies during the cancer care process with a particular focus on supportive care. Davis and Oakley-Girvan (2015) conducted a literature review to identify apps across the cancer care continuum (from prevention to survivorship) examining patient education and recommendations from randomized studies. Pandey et al. (2013) evaluated the availability and content of apps for cancer patients. Finally, Tabi et al.

(2019) reviewed medication management apps for oncology patients. However, these studies did not address patient preferences for the features of cancer mHealth apps.

The primary objective of this study was to review the scientific literature that describes the features and functions of mHealth apps designed for cancer self-management.

## **Methods**

This study employed a scoping literature review methodology. As stated by Munn et al. (2018), a systematic review is indicated when the purpose of the research is to compare clinical practices and/or inform decision-making, whereas a scoping review is indicated when the purpose of the review is to explore how research in the field is conducted and the kinds of literature available. As the purpose of this study was to explore the depth and breadth of research on mHealth app features for cancer self-management, a scoping review methodology was adopted for this study. Guidance was drawn from several sources including the seminal Arksey and O'Malley article from 2005, the Tricco scoping review guidelines from 2018, the McGowan Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) from 2020, and the Peters 2020 updates to the Joanna Briggs Institute Guidelines. The reporting in this manuscript follows the PRISMA-ScR extension guidance. This study protocol was not registered. This study was deemed not Human Subjects Research by the University of Arizona Internal Review Board.

### *Inclusion criteria*

This study included: manuscripts related to patient preference studies for cancer self-management using mHealth apps; utilization studies for cancer self-management mHealth apps; utility analyses for cancer self-management mHealth apps; and grey literature from online or trade publications related to consumer preference, utilization, or utility for/of cancer self-management mobile health software applications. Only studies for adults diagnosed with cancer were included. No limits were placed on the type of study considered for inclusion (e.g., experimental versus descriptive).

#### *Exclusion criteria*

Manuscripts not written in English were excluded. Pediatric studies were not included. Studies that focused on app development for cancer prevention, diagnosis, palliative care, or survivorship support were not included. Additionally, manuscripts published before 2010 were not included as technology evolutions would likely have rendered previous apps obsolete (Boulos et al., 2011).

#### *Search strategy*

Four databases were used for this review: PubMed/MEDLINE, EMBASE, CINAHL, and PsycINFO. The database searches were conducted between February 01, 2021, and April 01, 2021. A protocol was developed *a-priori* outlining search strategies including databases, websites, and search terms. Exploratory searches were conducted in PubMed and Google Scholar to gather potential search terms. Manuscripts from the exploratory searches were

reviewed, and keywords were collated to begin building a search strategy. Once a successful search strategy was built in PubMed, the Polyglot Search Translator was used to build additional searches for the other three databases (Clark et al., 2020). The final search strategy for PubMed is presented in Figure 2. Citation and reference searches were conducted for manuscripts meeting the inclusion criteria. A gray literature search was also conducted across technology trade publications (such as HealthTech Magazine) and health professional organization publications (such as American Society for Clinical Oncology and International Society for Pharmaceutical and Outcomes Research).

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("Neoplasms"[Mesh] OR "cancer"[ALL] OR "oncology"[ALL] OR "neoplasm*"[ALL]) AND ("Patient Preference"[Mesh] OR "Patient Satisfaction"[Mesh] OR "acceptability"[ALL] OR "utility"[ALL] OR "patient preference"[ALL] OR "patient satisfaction"[ALL] OR "usability"[ALL]) AND ("Telemedicine"[Mesh] OR "User-computer Interface"[Mesh] OR "mobile health"[ALL] OR "mHealth"[ALL] OR "mobile application"[ALL] OR "smart phone application"[ALL] OR "mobile app"[ALL] OR "smart phone app"[ALL] OR "smartphone application"[ALL] OR "smartphone app"[ALL]) AND ("Self-Management"[Mesh] OR "Self Care"[Mesh] OR "Treatment Adherence and Compliance"[Mesh] OR "Patient Compliance"[Mesh] OR "self-management"[ALL] OR "adherence"[ALL] OR "disease self-management"[ALL] OR "cancer supportive care"[ALL])
```

Figure 2. Scoping literature review PubMed search strategy.

### *Data extraction*

The research team developed title/abstract screening and full text review forms based on the inclusion and exclusion criteria above. Two independent reviewers (SV and SW) completed the title/abstract screening and full text review forms for the peer-reviewed and gray literature. If

consensus was not reached between the two reviewers, a third independent reviewer (a senior member of the research team) provided arbitration.

Data were extracted from the manuscripts meeting the inclusion criteria and collated in Microsoft Excel (2017). Data extracted from manuscripts included: author; title, publication date; study design; sampling type; cancer type; treatment; age of participants; features; availability/cost (free or subscription); design input; and patient preferences. One or more members of the research team verified the accuracy of the tabularized data and resolved any discrepancies. Finally, the features listed for each app were compared, highlighting similarities across platforms as well as features unique to each app.

## **Results**

The initial search identified 611 manuscripts. After the removal of duplicates 522 manuscripts remained for title and abstract review, with 51 undergoing full-text review. Seven manuscripts (referred to as studies hereafter) were included in the final scoping review. The outcomes of the database searches, title and abstract reviews, and full-text reviews (as well as reasons for exclusion) are presented in a PRISMA flow diagram of the manuscript selection process (Figure 3). Data extracted from the scoping review are presented as a table within the text (Tables 1 and 2). Table 3 contains categories of app features present in each article by first author, last name.

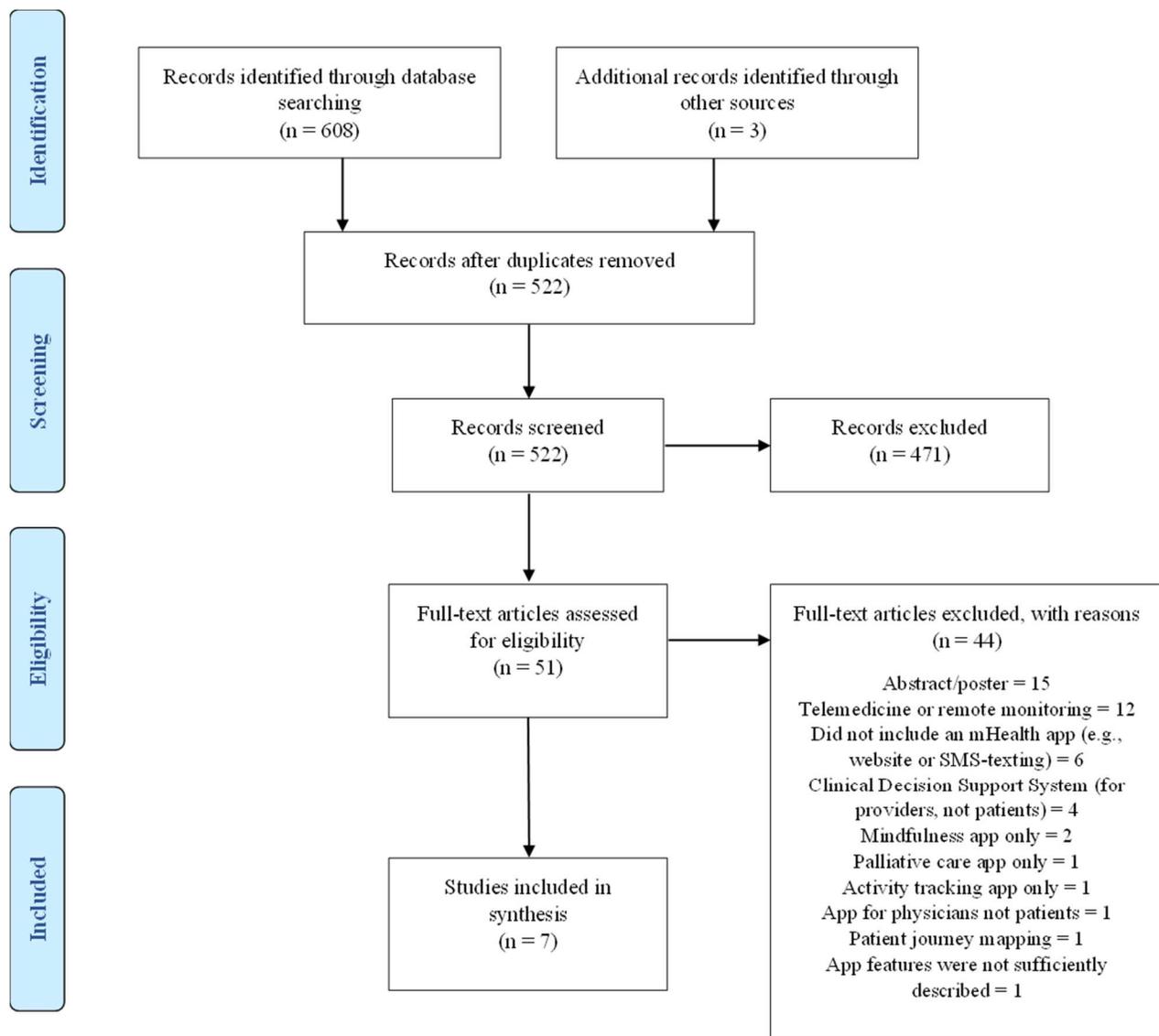


Figure 3. PRISMA\* flow diagram of the record selection process.  
\*Preferred Reporting Items for Systematic Reviews and Meta-Analyses

### *Study design and publication date*

While five of the included studies were descriptive (Birkhoff et al., 2018; Fishbein et al., 2017; Jacobs et al., 2020; Kongshaug et al., 2021; Tran et al., 2020), one study was experimental (Greer et al., 2020), and one study was quasi-experimental (Wang et al., 2020). The descriptive studies employed a variety of methodologies. Three were feasibility studies including

combinations of app trials, patient interviews, and expert focus groups (Birkhoff et al., 2018; Kongshaug et al., 2021; Tran et al., 2020). Two of the descriptive studies were usability tests including measures of acceptability or barriers (Fishbein et al., 2017; Jacobs et al., 2020). The experimental study compared the improvement of symptoms and medication adherence between two patient groups (using app versus standard care) (Greer et al., 2020). The quasi-experimental study compared patient care needs (such as psychological support and communications with the care team) between two patient groups, one of which received routine care and one with access to the patient app (Wang et al., 2020). Publication dates ranged from 2017 to 2021.

### *Sample size*

Sample sizes of included studies varied widely – ranging from 11 to 181, with descriptive studies including smaller samples and the quasi-experimental and experimental studies including 100 and 181 patients, respectively. Most studies, including the experimental and quasi-experimental studies, utilized convenience sampling (Birkhoff et al., 2018; Fishbein et al., 2017; Tran et al., 2020; Greer et al., 2020; Wang et al., 2020) or did not cite sampling methodology (Jacobs et al., 2019; Kongshaug et al., 2021).

### *Cancer type*

Four apps were developed to support a single subpopulation of cancer patients such as breast (Jacobs et al., 2019), gastrointestinal (Kongshaug et al., 2021), oral (Wang et al., 2020), or prostate cancer (Tran et al., 2020). The remaining apps were designed to serve a diverse cancer

patient population, including one app that was designed to support a wide range of diseases such as asthma and cardiac health (Birkhoff et al., 2018; Fishbein et al., 2017; Greer et al., 2020). Three apps were designed to support oral chemotherapy treatment regimens (Fishbein et al., 2017; Kongshaug et al., 2021; Greer et al., 2020). Two apps were designed to support mixed treatment regimens (Jacobs et al., 2019; Tran et al., 2020). One app each was designed to support radiation (Birkhoff et al., 2018) or surgical treatment (Wang et al., 2020).

### *Age of participants*

Four studies reported a mean age for participants (mean age ranged from 52 to 57 years) (Birkhoff et al., 2018; Jacobs et al., 2019; Greer et al., 2020; Wang et al., 2020) and one study reported a median age of 55 years (Tran et al., 2020). One study reported only an age range from 40-79 years (Kongshaug, et al., 2021) and one study did not specify participant ages (Fishbein et al., 2017).

### *App features*

App features described in each study varied from two to eleven, with a median of four features per app. The most reported feature was a symptom/side-effect tracker which was reported in six studies (Birkhoff et al., 2018; Fishbein et al., 2017; Kongshaug et al., 2021; Tran et al., 2020, Greer et al., 2020; Wang et al., 2020). While there were five emotional/social support features reported, they were found in only two apps. “Circle of support” and “Healthy dose” functionality were reported by Birkhoff (2018) and “Social support”, “Emotional support”,

and “Local resources” (which provided users with contact information for emotional and social support services in their community) were reported by Jacobs (2019). A total of 20 different types of app features were reported ranging from homepage and settings to medication adherence trackers and calendars. A total of five features were unique to a single app: Notes and questions (Fishbein et al., 2017), Notices of privacy and data usage (Fishbein et al., 2017), Personalized medication dosing schedule (with optional reminders) (Greer et al., 2020), Vital sign tracker (Birkhoff et al., 2018), and Weight tracking (Birkhoff et al., 2018).

#### *Availability/cost*

Two apps were noted to be free and publicly available for download (Birkhoff et al., 2018; Jacobs et al., 2019), two were only available to study participants or the patients of a particular cancer treatment facility at the time of publication (Greer et al., 2020; Wang et al., 2020), and the remainder did not specify availability (Fishbein et al., 2017; Kongshaug et al., 2021; Tran et al., 2020).

#### *Design input*

Three apps specified the inclusion of patients and health care providers during the design (Fishbein et al., 2017; Jacobs et al., 2019; Greer et al., 2020) while one app noted information technology and communications experts provided design input (Kongshaug et al., 2021). The remainder did not specify (Birkhoff et al., 2018; Tran et al., 2020; Wang et al., 2020).

### *Measure of acceptability*

The utility of technology for end users can be measured several ways including: acceptability (measuring the end-users experience), usability (assessing the functionality and performance by observing real users completing tasks), or qualitative data (reports from end users collected from interviews or focus groups). In the study by Birkhoff (2018), both usability and acceptability were reported. The overall usability score was 4.69 out of 7, though considerably higher among high school-educated patients (6.38) versus graduate degree-educated patients. There was no significant difference in reported usage over time. In the study by Jacobs (2019) acceptability was reported as a usefulness score (4.2/5), while engagement with the app over the study period was high, several improvements were suggested qualitatively, such as greater integration with local support services. The study by Wang (2020) reported acceptability among the intervention group over time. Baseline [odds ratio] scores were reported for intention to use (2.54), perceived usefulness (2.52), and perceived ease of use (2.32) compared to post intervention scores of 3.02, 2.95, and 3.01, a significant increase in all three aspects. Three studies presented utility as qualitative data [25,27,28]. Fishbein (2017) noted that usability and acceptability tests were performed but not reported, reporting instead that stakeholder feedback had been incorporated into the design from focus groups and alpha and beta testing as this was an app design protocol. Kongshaug (2021) reported the app provided patients with reassurance regarding correct oral chemo treatment, the app was used as a memory tool for discussing medication adherence and side-effects with the healthcare team, and patients were concerned about reporting less serious side-effects. In addition, health personnel expressed a positive attitude to integrate the tool in everyday work. Tran (2020) reported that patients valued the

emotional and well-being support over symptom reporting; patients requested incorporating patient online communities of support (such as Facebook or Reddit); patients were concerned with future data use and privacy; and requested data summary features to help them track the information they were entering over time. Finally, Greer (2020) did not report usability, acceptability, or qualitative data.

Table 1. Scoping literature review study characteristics.

First author	Date	Study type	Sample size	Sample type	Cancer type	Treatment	Age of participants
<b>Birkhoff</b>	2018	Descriptive - mixed methods feasibility (quantitative and qualitative)	60 recruited 32 completed	Convenience - sample of radiation oncology patients	not specified	Radiation	53.59 (Mean) 13.687 (SD) 22-77 (Range)
<b>Fishbein</b>	2017	Descriptive - evaluation of usability and acceptability	32 stakeholders Patient/families Oncology clinicians Cancer practice administrators Representatives of health system, community, and society)	Stakeholders were included as consultants (not participants) so no descriptive statistics are shown	Diverse cancer population	Oral chemotherapy	Not specified
<b>Greer</b>	2020	Experimental - randomized trial	91-mobile app 90-standard care	Convenience - patients receiving treatment at Massachusetts General Hospital Cancer Center (or 2 satellite sites)	Diverse cancer population	Oral chemotherapy	53.30 (Mean) 12.91 (SD) 21-88 (Range)

<b>Jacobs</b>	2019	Descriptive - usability and barriers	4 breast cancer survivors 7 healthcare professionals (cancer navigators and oncology nurses)	Not specified	Breast	Multiple: Surgery Radiation Chemotherapy Hormone therapy	Average 52
<b>Kongshaug</b>	2021	Descriptive - feasibility (app trial, patient interviews, healthcare professional focus groups)	14 patients recruited 9 patients completed (and were interviewed) 7 oncologists 7 oncology nurses	Not specified	Gastrointestinal cancer	Oral chemotherapy	~40-79 (Range)
<b>Tran</b>	2020	Descriptive - feasibility (app trial, patient interviews)	29 patients	Convenience - patients of Sidney Kimmel Cancer Center at Thomas Jefferson University Hospital	Prostate	Mixed	55 (Median) 45-70 (Range)
<b>Wang</b>	2020	Quasiexperimental - control group received routine care and education, experimental group received 20 minutes	100 patients	Convenience - patients of Far Eastern Memorial Hospital, New Taipei City, Taiwan	Oral	Surgery	57.01 (Mean) 8.87 (SD)

		education and guidance re: mHealth app (i.e. how to download, install, and use)					
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Table 2. Scoping literature review study characteristics, continued.

<b>First Author</b>	<b>Study Location</b>	<b>Features</b>	<b>Availability</b>	<b>Stakeholder Input</b>	<b>Patient Preferences</b>
<b>Birkhoff</b>		Appointment calendar Medication tracker Symptom tracker Journaling Daily mood diary Weight tracking Circle of support Vital sign tracker Healthy doses Tool library To-do list	Free and publicly available through developer website	App was previously designed and is available for a wide variety of patients - not oncology exclusive	Reported usability - overall 4.69, considerably higher among high school educated (6.38) versus grad school educated (3.87): Reported acceptability - there was no significant difference in app usage over time (i.e., no increase in uptake)
<b>Fishbein</b>		Homepage (medical treatment plan and healthy recipes) Symptom reporting Symptom reporting trends Education library	Not specified		Conducted but did not report usability/acceptability: Did implement features in app design based on stakeholder feedback through focus group and alpha/beta testing

		Notes and questions  Wearable fitness tracking device			
<b>Greer</b>		Personalized medication dosing schedule (with optional reminders)  Adherence and symptom reporting  Patient education (for symptom management and other cancer-related topics)  Fitbit integration (for tracking physical activity)	Patients of Massachusetts General Hospital Cancer Center	Key stakeholders (patients, clinicians, healthcare system)	Did not report usability/acceptability or patient preferences
<b>Jacobs</b>		Homepage  Overview  Local resources  Treatments  Day-to-day matters  Health and wellbeing  Social support  Emotional support  Favorites  Settings	Publicly available - Google Play Store	Cancer survivors and healthcare professionals	Tested usability average usefulness score was 4.2/5; patient engagement with app tasks was high, but several improvements were suggested - such as greater integration with local support services

<b>Kongshau g</b>		<p>Supporting adherence to medication (calendar view of medication plan, alerts and reminders for dose schedule)</p> <p>Management and reporting of side effects (with integrated patient decision support system to call nurse at cancer clinic if needed, summary of all side effects registered in each treatment cycle)</p>		<p>Information and technology communication system developers and designers, 10 colleagues of the research team</p>	<p>App provided patients with reassurance re: correct oral chemo treatment; app was used as a memory tool for medication adherence and side-effects; patients were concerned about reporting less serious side-effects; health personnel expressed positive attitude to integrate tool in everyday work</p>
<b>Tran</b>		<p>Notices of privacy and data usage for study purposes</p> <p>Symptom tracker</p> <p>Reminders to track symptoms (optional)</p>	Study only	Not specified	<p>Patients valued emotional and wellbeing support over symptom reporting; patients requested incorporating patient online communities of support (such as Facebook or Reddit); patients were concerned with future data use and privacy; patients requested data summary features to help them track the information they were entering over time</p>

<b>Wang</b>		<p>Latest news (latest communications to patients after surgery, links to YouTube videos on oral health education and head and neck rehab, link to patient groups through LINE app)</p> <p>Medical information (info on oral cancer, oral cancer treatment, pain information, hospice care, other supporting personnel or cancer treatment institutions)</p> <p>Self-recording (enables patients to record their own postoperative info and symptoms e.g., date, body temp, pain level, oral ulcer, vomiting, skin reactions, diarrhea)</p> <p>Revisit reminders</p>	Not specified	Not specified	<p>Acceptability of the app was measured through intention to use, perceived usefulness, and perceived ease of use (TAM model); baseline scores for experimental group were 2.54, 2.52, and 2.32; after intervention group scores were 3.02, 2.95, and 3.01 - acceptability significantly increased in all three aspects of TAM; patients reported greater reliance on app information over leaflets distributed by health staff (boring and cumbersome)</p>
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Table 3. Categories of mHealth app features in scoping literature review by author.

Features	Birkhoff	Fishbein	Greer	Jacobs	Kongshaug	Tran	Wang
Symptom tracker	■	■	■		■	■	■
Emotional/social well-being	■			■			
Medication tracker	■		■				
Reminders		■	■		■	■	■
Tools and settings	■			■			
Landing page		■		■			
Education		■	■				■
Health and fitness		■	■	■			
Calendar	■				■		
Medical/treatment information				■			■
Privacy/data usage		■					
Notes & questions		■					
Personalized dose schedule			■				
Journaling	■						
To-do list	■			■			
Weight tracking	■						

Patient decision support							
Vital sign tracking							

**Discussion**

In total, seven studies published from 2017 to 2021 were included for analysis. Studies varied in methodology, from descriptive to experimental, and size, with subject sizes ranging from 11 to 181. Additionally, apps were developed to address the needs of a heterogeneous patient population; some address the needs of a single cancer indication or treatment, and others provide support across the spectrum of cancer diagnoses. Likewise, the number of features per app varied from two to eleven with a median of four – with the most reported feature being a symptom tracker. Lastly, several studies reported patient acceptability or preference data for the app and/or the features with acceptability (assessed through survey or interviews) most frequently reported.

The objective of this study was to understand the features implemented in cancer self-management apps. Symptom tracking, education/information, and medication tracking were three of the most frequently reported features, each of which are discussed in turn below.

Symptom tracker was the most reported feature across the manuscripts in this review, reported in six of seven manuscripts. Cooley et al. (2017), noted that symptom tracking (particularly with eHealth applications) was relevant to improved patient outcomes in cancer treatment. Similar results were shown by Lu et al. (2021), in which a systematic review was conducted to evaluate the use of mHealth apps to track patient-reported cancer outcomes, such

as symptom reporting. Their search of the iOS Apple Store and Android Google Play identified 11 cancer-specific apps with symptom tracking features. Further details of these features were explored. Some symptom trackers offered the ability for patients to: add symptoms not already listed; record symptom severity; add notes; provide a graphical summary; or export data to a caregiver or health professional. Two apps in our study were able to provide symptom trend-reports and graphical information (Fishbein et al., 2017; Kongshaug et al., 2021) but only one specifically noted the ability to log symptom severity (Fishbein et al., 2017). Further studies may seek to examine patient preferences for symptom trackers such as the utility derived from displaying symptom reporting trends over time.

This study found that patient education features were reported in three studies (Fishbein et al., 2017; Greer et al., 2020; Wang et al., 2020). Similarly, Richards et al. explored the importance of patient education within mHealth apps conducting a systematic review in 2018 to assess how patients used their mobile devices to access information to support outpatient disease management (Richards et al., 2018). Fourteen different interventions were identified across 23 published studies. The education-related features described by Richards et al. were related to treatment and did not meet the full range of patient information needs regarding treatments and symptom-management. In contrast, the education features identified in our study attempted to meet a broader spectrum of information needs including symptom management and other cancer-related topics (such as nutrition). Likewise, three of the studies included in this review included a homepage (at least one of which provided health recipes and news items). Finally, our study identified a total of five emotional or social support features that were reported within two apps (including information on local patient and caregiver support groups and services) (Birkhoff et al., 2018; Jacobs et al., 2019). While many of the app features were not described as primarily

providing cancer care information, several the features included information to support patients with disease self-management.

Medication trackers were not typical of the offerings of cancer self-care apps included in our study, as they were present in only two studies. Similarly, Ross et al., conducted a scoping review in 2018 to better understand mobile phone apps that were designed to enhance medication adherence to oral chemotherapy. Ross et al. (2018), identified five studies with electronic medication adherence interventions, however, only two utilized an mHealth app (the others were SMS text message-based). Alarms and reminders were used in both apps to increase patient medication adherence. Likewise, alerts and reminders were identified in four apps in our study (Kongshaug et al., 2021; Tran et al., 2020; Greer et al., 2020, Wang et al., 2020). Like our study, none of the apps included in the study by Ross et al. (2018), were noted to contain a feature for tracking medication taking behavior trends over time. A 2016 study by McNamara noted the difficulty in managing patient oral oncolytic medication adherence and a 2015 article by Burhenn and Smudde advocates for tools (such as smartphone apps) to aid patients in medication adherence.

Despite the growing number of oncology apps, challenges of access do remain for patient seeking to utilize mHealth for cancer self-management. Our study noted that several apps were available only to the patients of a particular cancer center or health system. Similarly, a 2020 study by Ana et al. noted that while there are an increasing number of clinical trials aimed at increasing patient medication management through the use of an mHealth app, many of these apps are removed from app stores after the trial ends. Thus, potential resources remain out of patient reach.

### *Limitations*

This study was a scoping review, rather than a systematic review, therefore a quality assessment was not conducted for the studies meeting the inclusion criteria. Future research could consider conducting a systematic review, assessing the quality of studies included in the review may lead to further insights. This study specifically sought information on smartphone apps – not SMS/text/web apps. Accordingly, a narrow range of inclusion dates were utilized to account for current smartphone operating systems. While not a specific inclusion criterion, patient preference was an area of research interest and not all studies included reported such.

### *Future research*

The information found in our study may be of value as cancer apps are continuously developed and updated. Researchers have not always utilized the preferences of patients in the design of apps. Many of the app features identified in this study included optional calendar reminders, alerts, or trend graphs, though how useful patients find these optional functions is less clear. Additionally, there may be key features that would enhance utilization that are, yet, undiscovered.

Further assessment of available features should be conducted among subject matter experts in the fields of mHealth cancer app development and cancer clinical care – to explore whether the features currently available are useful and relevant for patients (i.e., meet patient preferences). This may enable development of mHealth apps that better meet patient needs for

disease self-management, both from a technical and clinical perspective. Further clarity is needed regarding whether currently available features are utilized by patients. In addition, some features are heterogeneous across apps. For example, some medication trackers also feature optional alerts when medication should be taken or reminders to track medication adherence, but it remains unclear how many patients use these options or how often. This information could be transformed into a discrete choice experiment to better understand patient preferences for app features. Lastly, this can inform future app development or existing app revision.

## **Conclusions**

While the number of cancer-related apps available for download continues to rise, further exploration of patient preferences for app features could result in apps that better meet patient disease self-management needs. Currently there is a lack of consensus regarding the presentation of information on patient input into the app design process, reporting best-practices may increase comparability of research. Future research may also include evaluation of mHealth apps upon development completion from an end-user (patient) perspective.

## **Chapter 4: EXPERT OPINION SURVEY**

### **Introduction**

Since the advent of the smartphone a profusion of mobile health software applications (mHealth apps) has been made available to patients. By a 2017 estimate 325,000 mHealth apps were available for download. (Pohl M, 2017, Tarricone, 2019) mHealth apps have been developed for a wide variety of health conditions including diabetes (Conway et al., 2016), chronic arthritis (Geuens et al., 2019), and orthopedic surgery (Dattilo et al., 2017). mHealth apps for cancer span the cancer continuum from prevention and diagnosis to treatment and survivorship. (Chao, 2017; Benze, 2019). Within the broad range of cancer apps available, cancer patients can find apps to aid in self-managing disease symptoms, medication side-effects, and medication adherence. However, apps designed to educate about cancer and aid in cancer self-management accounted for just 5% of mHealth apps available in 2019. (Tarricone, 2019)

A literature review by Ghani et al. (2020) shows mixed results across 11 cost evaluations of mHealth apps to reduce costs associated with chronic disease management: including intervention costs, physician visit costs, and cost for follow-up calls. In the case of oral chemotherapies to treat cancer, home-based treatment is associated with improved quality of life (Weingart, 2008). However, to achieve these benefits, patient adherence to oral chemotherapies is critical. (Fishbein, 2017)

A 2019 study by Tarricone et al. revealed that a minority of physicians treating cancer patients utilized mobile health apps to support patients in the treatment and follow-up processes (such as side-effect management and compliance monitoring. If cancer support apps are to reach

their potential in patient self-management of disease (Schera, 2018), understanding provider perceptions of the usefulness and relevance of app features is critical.

A previous scoping literature review identified seven apps that were developed for cancer patient self-management (primarily symptom and medication adherence tracking but some including additional features, for example emotional wellbeing and social support and/or fitness and nutrition tracking) which listed and/or described the features included with the app. (Vaffis, 2022) The review noted that only three studies disclosed the stakeholders involved in determining app features and content. Markedly, patients were only named twice as part of the app development stakeholder group. A study by Fishbein et al. included in the literature review suggested a 5-step iterative process which informed development of the app which relied on expert, clinician, and patient input.

Previous research lacked clarity on the expert input process. There was also lack of comparison between experts' opinions and patients' preferences. This study aimed to define mHealth app features that were important and relevant to cancer patients for disease self-management through a survey of subject matter experts.

## **Methods**

### *Study design*

In a previous study we identified 40 mHealth app features through a scoping literature review (Vaffis et al., 2022). These 40 features were collated into groups according to their function. For example, medication tracking features were collated into a single group. This

resulted in nine groups and these groups formed the basis of questions for the expert opinion survey. The nine groups are: landing page, tracking symptoms, medication adherence and/or tracking, education and news, calendars and planning, reminders, wellbeing and emotional/social support, physical fitness and nutrition, and tools and settings.

The survey consisted of an introduction section, explaining the purpose of the survey and outlining the preceding literature review as well as providing instructions and defining terms used in the survey questions. The survey consisted of nine multiple choice questions. Each question presented a group of app features noted in the literature that offered similar functions (i.e., landing page; tracking symptoms; medication adherence/tracking; education and news; calendars and planning; reminders; wellbeing and emotional/social support; physical fitness and nutrition; tools and settings). For example, questions presented groups of features noted in different peer-reviewed literature regarding the ability to track symptoms or calendars. The number of functions per group varied from two to seven. Additionally, a function could be listed in two different categories as sometimes it was described in the literature as doing more than one thing. For instance, a medication tracking function could also contain a reminder function to take or track medication adherence thus placing it in both the medication tracking/adherence category and the reminders category. After each category question, experts were given the opportunity in each question to add app features that did not appear in the list of options. Experts were asked to read the list of related features and select all the features in the list they believed would be useful to patients in self-managing disease. Features were described using the language from their original publication in the peer-reviewed literature. No demographic questions were posed to the participants as they had been selected for their expertise in the relevant fields. Nine questions were created relating to the nine categories of features collated from the 40 app features

identified in the literature review. For example, the category of landing page resulted in the following question: “ The following mHealth app features were identified in the literature and relate to the landing page (first page viewed on app). Please select ALL the app features from the following list that would be useful to patients.” Beneath this question appeared the list of related features with their descriptions from the literature, such as: “Welcome screens (explain study purpose and how to use app)”. For a copy of the survey, see Appendix A.

As a final preparatory step before launching the survey, the questionnaire was subject to a read-aloud, think aloud session with a subject matter expert. The survey developer read each question aloud to an expert in the field of cancer treatment to assure that each question was interpreted as intended by the research team.

#### *Inclusion/exclusion criteria*

This study utilized a purposive sample of experts in the fields of mHealth app development, cancer patient communications, and clinical treatment. Participants were identified through their work in developing mHealth apps specifically for cancer patients, their research in communications with cancer patients, and their research with cancer patients in the clinical setting. The target sample size was ten to fifteen experts.

#### *Participant recruitment*

A purposive sample of experts in the fields of cancer research, cancer clinical treatment, and cancer app development were recruited. Experts were identified through past work with the research team and provided referrals to other potential participants. An email invitation was sent to all potential participants. The email explained the purpose of the survey, to determine the importance and relevance of app features identified in the preceding literature review as well as allow the participants the opportunity to include features they perceived would be important and relevant to patients that were not identified in the literature. Those experts who agreed to participate were emailed a link to the web-based survey. Participants were not compensated for their participation.

#### *Data collection and analysis*

The survey was developed and conducted in Qualtrics (Qualtrics, Provo, UT). Data from the survey were collated in Qualtrics. All responses were stored in the Qualtrics password protected survey platform. Microsoft Word (2017) was used to tabulate and qualitatively analyze de-identified responses. Responses to the nine rating scale questions were quantitatively analyzed. Responses to the open-ended questions which appeared after each rating scale question were qualitatively analyzed. The data were analyzed to determine the attributes with the highest relevance for mobile health software applications for cancer patients according to the subject matter experts (as measured by lowest composite score when a rating of 9 out of 9 is the most relevant). The survey was conducted between May 5, 2021, and May 25, 2021. Participants were allowed to exit and return to the survey until it was completed. This study was deemed not Human Subjects Research by the University of Arizona Internal Review Board.

## **Results**

### *Participant characteristics*

A total of nine participants completed the survey. Nearly 78% of participants (n = 7) were female. Five organizations were represented by participants: two participants represented a professional organization and were involved in the development of the organization's mHealth app for cancer patients, two participants were academic researchers in health communications with cancer patients, two participants represented two private mHealth cancer app development organizations and three participants were involved in cancer clinical care.

### *Response patterns*

All participants responded to each of the nine rating questions. Responses to each are presented below according to the order in which the question about each category appeared in the questionnaire. See Table 4 for results.

### Landing page

Three features were presented in the question related to mHealth app landing pages, making it the second smallest category. The landing page is the first screen displayed to a user when the app is opened. Only one landing page was described as providing a directory for users to access other app features. The other two landing pages provided an app how-to page and a

medication treatment plan and healthy recipes. Each of the three features was endorsed seven times. This was the only question in which each feature was endorsed at the same level.

### Tracking symptoms

Six features were presented in the question related to tracking symptoms. This was the second largest category of features. Features described as providing weekly reporting were endorsed less often than features described as providing daily reporting. Additionally, features which included the option to contact the clinical care team received higher endorsement. Endorsements were evenly divided with three features receiving eight endorsements and three features receiving seven endorsements.

### Medication adherence and/or tracking

Medication adherence was the smallest category of features with only two identified from the literature. “Medication tracker” received universal endorsement, while “Adherence and symptom reporting module” received seven endorsements. Tracking actual medication usage rather than providing a weekly estimate received higher endorsement.

### Education and news

Education and news was the largest category with seven features presented. Features described as providing general information received fewer endorsements than features described as providing personalized information (for example, resources appearing as patients transitioned between treatment phases). Two features (“Education library” and “Information recommendations”) received universal endorsement, one feature (“Resource view”) received 8 endorsements, while the remaining features received seven endorsements each.

### Calendars and planning

Five features were presented in Calendars and planning. This category tied with Wellbeing and emotional/social support for the shortest range in the number of words per feature descriptions (8 words between the shortest and longest descriptions). Three features received universal endorsement and two features received eight endorsements each.

### Reminders

Five features were presented in the Reminders category. Of these five features, one received universal endorsement, three received eight endorsements, and one received seven endorsements.

### Wellbeing and emotional/social support

Wellbeing and emotional/social support contained features which ranked among the lowest rated. “Healthy doses” received only five endorsements and “Journaling” received only six. However, “Daily mood diary” and “Circles of support” each received eight endorsements.

### Physical fitness and nutrition

This category presented four features, of which one was universally endorsed and three were endorsed by eight participants. Respondents universally endorsed “Wearable fitness tracking device”, the description of which specified integration with a Fitbit brand tracker but did not universally endorse “Fitbit” integration.

### Tools and settings

Tools and settings presented four features. Two features (“Self-recording” and “Tool library”) received eight endorsements, “Notes and questions” received seven endorsements, and “Notices of privacy and data usage” received only five endorsements.

Table 4. mHealth app features by level of expert endorsement, ranked.

<b>Features</b>	<b>Endorsements (N = 9)</b>
Medication tracker (adding medications to the list, set reminders, and document when a medication has been taken, postponed, or missed, and the reasons why)	9
Education library (symptom management, social networking, and support resources, nutrition, and clinical contact information)	9
Information recommendations (each user profile includes all treatments and treatment dates. These dates signal a transitional event that generates recommendations based on the patient’s treatment path)	9
Appointment calendar (tracking of all doctor appointments and treatments)	9
To-do list (allows users to make a list of tasks that need to be completed)	9
Notes and questions (store notes and questions for future clinical visits)	9
Personalized medication dosing schedule (with optional reminders)	9
Wearable fitness tracking device (stream data from Fitbit devices to app, display daily step counts, and allow users to set daily step goals and display progress towards those steps)	9

Management and reporting of side effects (with integral patient decision support system to call nurse at cancer clinic, if needed, summary of all side effects registered in each treatment cycle)	8
Symptom tracker (documentation of and rating of their general wellness or whether they are experiencing any side effects of their health condition or treatments; a graph is generated to show trends over time)	8
Symptom reporting (weekly and real-time symptom reporting for common symptoms and treatment side effects, with algorithms that personalize symptom management suggestions or enable participants to call their care team directly from the app)	8
Resource view (resources appear one week before a new treatment, or at the end of a treatment, to help a patient learn what to expect and prepare for this change)	8
Supporting adherence to medication (calendar view of medication plan, alerts, and reminders for dose schedule)	8
Personalized medication dosing schedule (with optional reminders)	8
Revisit reminders (provides a reminder function for patients to remember to return to the hospital)	8
Medication tracker (adding medications to the list, set reminders, and document when a medication has been taken, postponed, or missed, and the reasons why)	8
Supporting adherence to medication (calendar view of medication plan, alerts, and reminders for dose schedule)	8
Daily mood diary (tracking daily moods from a collection of 11 positive and 11 negative emotional identifiers, adapted from PANAS [Positive and Negative Affect Schedule] mood scale)	8

Circles of support (adding any person to view activities or progress tracked on the app as directed by user)	8
Fitbit integration (for tracking physical activity)	8
Weight tracking (tracking of weight and the ability to generate a graph over time for trends)	8
Vital sign tracker (tracking of common vital signs such as pulse and blood pressure and the ability to graph trends over time)	8
Self-recording (enables patients to record their own postoperative information and symptoms e.g., date, body temperature, pain level, oral ulcer, vomiting, skin reactions, diarrhea)	8
Tool library (additional set of mini-apps that users can browse and pull into their home screen based on their preferences; the categories within the tool library consist of organization and reminder, tracking and monitoring, nutrition, and physical activity)	8
Homepage (contains the following links: Overview, Local resources, Treatments, Day-to-day matters, Health and wellbeing, Social support, Emotional support, Favorites, Settings)	7
Welcome screens (explain study purpose and how to use app)	7
Homepage (medication treatment plan and suggested healthy recipes)	7
Symptom reporting trends (graphical display of weekly symptom trends, customized for each patient and their medical oncologist)	7
Symptom assessment (validated health-related quality of life surveys relevant to prostate cancer completed once per week)	7

Adherence and symptom reporting module (users rate medication adherence on a weekly basis from 1-100% as well as "very poor" to "excellent" and report symptoms experienced on a weekly basis, with referral to additional education resources based on symptoms reported and severity)	7
Adherence and symptom reporting module (users rate medication adherence on a weekly basis from 1-100% as well as "very poor" to "excellent" and report symptoms experienced on a weekly basis, with referral to additional education resources based on symptoms reported and severity)	7
Patient education (for symptom management and other cancer-related topics)	7
User Survey (may be completed at any time to immediately receive information related to current questions or challenges; information is pulled from a database of over 300 information resources from American Cancer Society, breastcancer.org, and cancer.net)	7
Medical information (information on oral cancer, oral cancer treatment, hospice care, other supporting personnel, or cancer treatment institutions)	7
Latest news (latest communications to patients after surgery, links to YouTube videos on oral health education and health and neck rehabilitation, links to patient groups through LINE app)	7
Reminders to complete survey/track symptoms (optional)	7
Notes and questions (store notes and questions for future clinical visits)	7
Journaling (list of guided topics, such as what am I thankful for today, and a free writing space to journal about any topic)	6

Healthy doses (library of motivational and inspirational quotes with images on the topics of gratitude, optimism, love, humor, and mindfulness)	5
Notices of privacy and data usage	5

### *Ranking of responses by level of endorsement*

Eight features were given universal endorsement from nine of nine participants (100% of participants). Sixteen features were given endorsement by eight of nine participants (89% of participants). Thirteen features were given endorsement by seven of nine participants (78% of participants). One feature was endorsed by six of nine participants (67% of participants). Finally, two features were given endorsement by five of nine participants (56% of participants).

One anomaly noted in the data related to features which fit into two categories. Two features included descriptions of their functionality which placed them in two categories simultaneously. The first “Adherence and symptom reporting module” appeared in both the “Tracking symptoms” and “Medication adherence and/or tracking” categories. In both categories the features was endorsed at the same level by seven of nine respondents (78%). However, the “Notes and questions” feature was listed in both the “Calendars and planning” category, where it was endorsed by nine of nine respondents (100%) and the “Tools and settings” category where it was endorsed by seven of nine respondents (78%).

### *Qualitative analysis*

Open-ended questions were not highly utilized by respondents. Two questions received one open-ended response each. Question 2 regarding features for tracking symptoms received the following response, “why track them give me something as the patient that will help me.” Question 6 regarding features for reminders received the following response, “reminders to refill ongoing prescriptions based on 30/90-day supply”.

## **Discussion**

The data resulting from this survey of experts in cancer mHealth apps and clinical treatment were unexpectedly homogenous. Only two questions included features that were not endorsed by seven or more participants. Question 7 had two features not selected by seven or more participants (Journaling and Healthy doses) and Question 9 had one feature not selected by seven or more participants (Notices of privacy and data usage). Each category of features was accompanied by an open-ended question allowing the respondents to introduce features not identified in the literature. Through these options were only used twice, one new feature did appear “reminders to refill ongoing prescriptions based on 30/90-day supply”.

We anticipated a more diverse range of endorsements within and across categories. Whereas we might have expected the expert panel to rate the categories of “Medication adherence and/or tracking” or “Tracking symptoms” most highly, the highest rated categories were “Calendars and planning” and “Physical fitness and nutrition”. These results are counter-intuitive given the shown association between lower costs and improved quality of life and increased use of mHealth apps for medication adherence and symptom and/or side-effect monitoring (Tabi et al., 2019). Furthermore, where we might have expected to find the “Landing

page” or “Tools and settings” categories to rank toward the bottom, the category of “Wellbeing and emotional/social support” was ranked lowest by the experts. This may suggest that the option for mHealth apps to support patients’ needs beyond strictly medical concerns was of less importance to the experts compared to patient education and medication adherence or may indicate that the list of features identified in the literature were deemed unsuitable to meet patient’s needs. Without the use of the open-ended questions to introduce features more appropriate to this category it might be the case that the experts valued this category lowest regardless of the features available.

The purpose of this study was to identify mHealth app features from the literature, or through open-ended responses from experts, that were best suited to meeting patients’ needs in cancer self-management. However, the results did not aid us as much as expected in narrowing the levels of the attributes identified in the literature review or in identifying features that were not noted in the literature. All features, though some were endorsed at lower levels than other, were endorsed by at least 50% of respondents.

One new feature did appear, “reminders to refill ongoing prescriptions based on 30/90-day supply”. However, it is unclear whether this fits into the already listed feature of “Supporting adherence to medication” with its description of “calendar view of medication plan, alerts, and reminders for dose schedule”.

There is a paucity of peer-reviewed literature on the incorporation of expert opinion in the development of mHealth apps generally and mHealth cancer apps specifically. Several notable examples are included here, but discussion of how expert opinion was collected remains scant. In our previous work (Vaffis et al., 2022) only three of seven mHealth cancer apps in the

review included health care or academic input in app development and the remainder did not specify which stakeholders had input. Ahmed et al. (2018) conducted a review of 681 medication adherence apps available in the Apple iOS and Google Play app stores to understand medical professional input on app development. Only 84 of 681 stated health care provider input was utilized in development. Similarly, Tabi et al. (2019) reviewed 328 mHealth apps aimed at helping patients understand and take medication available Apple iOS and Google Play app stores. The majority were developed by software industry (73%) (239/328) without input from healthcare professionals, 15% (48/328) were codeveloped with health care professionals, and 2.1% (7/328) were developed in conjunction with academics. Finally, Tarricone et al. (2019) conducted survey among cancer patients and cancer care clinicians to understand patterns of mHealth cancer app usage. A roundtable workshop followed to explore the survey findings (participants at the workshop included patients, clinicians, app developers, and experts in medical communications and health education, as well as representatives from the pharmaceutical and medical technology, and telecommunications industries, payers, and policymakers). Experts at roundtable workshop agreed that apps were not developed with patients in mind and app functionalities often do not meet patient expectations and needs.

### *Practice implications*

The results of this study demonstrate that app developers, researchers, and clinicians believe current mHealth apps include features that are meaningful and useful to patients.

If experts believe the features of apps are relevant and useful to patients, they may be more likely to support patient use of these tools. Increased patient use of apps to maintain

medication adherence has been shown to reduce costs and improve quality of life (Basch et al., 2015). Though the objective of our study was not app development, nevertheless we sought to understand expert opinion of features in mHealth cancer apps in the literature. The literature points to a need for health care providers to be involved in app development and surveys may be a useful tool in collecting valuable expert input.

### *Limitations*

This study utilized a convenience sample of experts in the fields of cancer mHealth app development, patient communications research and clinical care. While representation from practitioners across several key fields related to cancer mHealth apps, the total number of participants was small and may not be representative of all practitioners in this field. However, experts were represented from a number of fields relevant to mHealth cancer app development such as mHealth cancer app developers, academic researchers in communications with cancer patients, and clinicians in cancer treatment. In addition, this sample was limited to practitioners in the United States. Finally, participants did not often utilize the open-ended response option to include app features which may benefit patient uptake of mHealth apps.

### *Future research*

This study asked practitioners to estimate the utility of app features for patients but did not incorporate patient preferences directly. As a proxy measure the current study leaves room for future studies to incorporate patient preferences for these app features directly.

## **Conclusions**

Experts identified that almost all levels of mHealth app attributes identified in the literature search would be of value to patients in self-managing cancer.

## **Chapter 5: PATIENT CHOICE-BASED CONJOINT SURVEY**

### **Introduction**

Estimates for the number of mobile health software applications (or mHealth apps) have increased dramatically in the past ten years from 13,500 health apps available in the Apple iOS app store in 2012 (mobilehealthnews,2012; Bender et al., 2013) to more than 325,000 health apps available in the Apple iOS and Google Play app stores in 2017 (Pohl M, 2017; Upadhyay et al., 2021). This aligns with the increasing number of people in the United States (US) with access to smartphones and broadband internet (Smith et al., 2017). Additionally, a survey of 375 cancer patients found that about half were willing to use a cancer mHealth app to aid in disease self-management (Kessel et al., 2017). Despite this unprecedented proliferation in, access to, and interest in mHealth tools, there remains a lack of evidence that mHealth apps directed toward cancer patients lead to improved outcomes (Osborn et al., 2019).

Two identifiable barriers may be undermining the potential of mHealth cancer apps to improve outcomes. First is the lack of apps directed at patients, despite the number of mHealth apps. Upadhyay et al. (2021) identified 794 oncology-specific apps in the Apple iOS and Google Play app stores, of which, only 27% were for patient use (as opposed to 45% for clinician use and 28% for use by the general public). Likewise, Charbonneau, et al. (2020) studied 123 cancer apps and found the primary purpose of 50% of the apps was education while only 12% were intended for disease management. Additionally, Lu et al., 2021, found only 11 cancer-specific apps with symptom tracking features. The second barrier may be the rate of app uptake and likelihood of long-term app use. For example, Perez S (2019) discovered a quarter of those who download mobile apps discontinue visits after only one use. In addition, Kayyali et al. (2017) found most people abandon app use after four interactions. While the suggested reasons for these

observations vary, app use may be determined by the user's assessment of the app's capabilities to help them reach their health goals (Vaghefi and Tulu, 2019) or digital tools may need be used habitually to deliver expected outcomes (Limayem, Hirt, and Cheung, 2007).

A third potential barrier is less well understood; whether the features currently available in mHealth cancer apps are the features patients want. Richards et al. (2019) noted that during semi-structured feedback interviews about an informational cancer app, patients suggested a variety of features that might increase the app's utility (a symptom diary to track when during treatment symptoms were likely to occur so they could plan diet and social activities around symptom occurrence, features to facilitate information exchange in clinical visit, and links to social media to exchange information with other patients). Vaffis et al., 2022 found that patient preferences were not often reported in app development studies. Currently, there is a lack of evidence assessing patient preferences in mHealth cancer apps for disease self-management.

We aimed to explore the utility of discrete choice methods for understanding patient preferences mHealth cancer apps. Utilizing our previous research on mHealth app features, we developed a survey containing a choice-based conjoint exercise to reveal patient preferences for mHealth app features.

## **Methods**

### *Discrete choice experiment*

Discrete choice experiments are a stated preference method to elicit participants' opinions of the desirability of the characteristics (attributes) of goods and services. Key to

discrete choice methodology is establishing the attributes, and the levels which further describe them, through exploration of literature and expert and/or consumer input.

Attributes and levels were determined through two previous stages of research. First a scoping literature review was conducted to explore how mHealth apps and their features/functions were described in published literature (Vaffis et al., 2022). The literature review was followed by a survey of experts in the fields of cancer mHealth app development, research on communications with cancer patients, and cancer clinical care. This served as a source of content validity evidence for the attributes and levels identified in the literature review. The survey presented experts with the potential attributes and levels for the patient-focused choice-based conjoint survey through a series of questions presenting the features and functions of mHealth apps found in the literature review. The experts were asked to rate how useful and relevant they considered them to be for patients in disease self-management. There were nine questions, each followed by an open-ended question for the experts to write-in additional features they felt may be useful to patients that were not identified in the literature search.

Results from the survey were quantitatively and qualitatively analyzed to determine the five most relevant features (attributes) and three to four functions of each feature (levels). These features and functions deemed most relevant and useful to patients by the experts formed the basis of the choice-based conjoint exercise in the patient survey.

### *Survey questionnaire*

#### Introduction questions

Three introduction questions opened the survey. Participants were asked whether they had used an mHealth app for any purpose, whether they had used an mHealth app for cancer, and if they were to use an mHealth app for cancer, which functions they might consider useful. These questions were included as a means to calibrate the results of the choice-based conjoint exercise. Participants had the option to select yes or no for the first two questions and to select from a rating scale “Very useful”, “Somewhat useful”, or “Not very useful” for the third question. .

### Choice-based conjoint exercise

The discrete choice experiment was designed as a choice-based conjoint (CBC) exercise in Lighthouse Studio 9.12.1 (Sawtooth Software). The CBC exercise consisted of nine choice tasks in which respondents compared the features of hypothetical mHealth apps for cancer self-management. Respondents were asked to compare the functions of the five features and select the group of functions they preferred. There were five attributes: Symptom tracker, Medication tracking, Calendar, Education, and Well-being. Symptom tracker, Medication tracker, and Calendar had five levels each. Education had three levels while Well-being had four levels.

### Demographic questions

To determine the representativeness of the sample compared to US adult cancer patients, five optional demographic questions were used at the end of the survey. These included: age; gender (female, male, non-binary/third gender); Hispanic, Latin, or Spanish origin; race; and region of the country where they reside (Midwest, Northeast, South, or West; with a list of states included in each region). All questions offered the option “Prefer not to say”. Participants had the option to select only one response from each list of options.

### *Participant recruitment*

Participants were recruited via email by Qualtrics XM. Participants were recruited from various sources, including website intercept recruitment, member referrals, targeted email lists, gaming sites, customer loyalty web portals, permission-based networks, and social media, etc. Participants were sent an email invitation or prompted on the respective survey platform to proceed with a given survey, which provided a hyperlink to take the respondent to the survey. One hundred cancer patients and survivors were recruited to complete the final survey. A pilot test of the survey prior to launch included ten additional participants. Participants were screened based on whether they had ever been diagnosed with cancer – regardless of whether they were in treatment or had completed treatment. Participants were aged 18 or over.

### Pilot test

Face validity was tested for the patient survey using the input of several experts in the field of survey design and psychometrics. Only minor changes to the survey wording resulted from the face validity testing. A pilot test was conducted with 10 participants, recruited by Qualtrics XM, who met the study inclusion criteria (ever diagnosed with cancer and over 18 years of age). The pilot test was run in Qualtrics XM. The results were reviewed by the research team to determine whether any changes were necessary to the survey wording or flow. The pilot test did not result in any changes to the survey instrument.

### *Latent class analysis*

This analysis utilized a latent class (LC) multinomial logit model to identify different segments (classes) of respondents based on response patterns. In latent class analysis random

estimates of each segment's utility values are selected. Each respondent's data are fit to the utility values to estimate the probability of a respondent belonging to that class or segment. This analysis was run using two to five classes with five replications per class. Convergence was facilitated by running up to 100 iterations per class, the default settings in Sawtooth.

Membership to a class or segment is a probability not a definitive assignment. Therefore, the most appropriate model must be chosen based on the evidence in fit statistics and diagnostics. Fit statistics include Akaike information criterion (AIC), Consistent Akaike information criterion (CAIC), and Bayesian information criterion (BIC). According to an LCA best-practice article by Weller et al. (2020), BIC is the most often reported fit statistic. BIC favors parsimonious models and lower BICs are indicative of increased model fit. With other information criterion, such as the AIC and CAIC, lower results also indicate increased model fit.

Beyond fit statistics, a number of diagnostic statistics should be considered when selecting the final model (though these diagnostic criteria are not suitable for model selection in the absence of fit statistics) (Weller et al., 2020) First, membership probability is the average probability of the class model accurately predicting class membership for individual respondents (Weller et al., 2020). Membership probability ranges from 0 to 1 and 0.9 is suggested as ideal (Muthen and Muthen 2000). However, if other criteria are met and the model is theoretically supported, then values between .80 and .90 are acceptable (Weller et al., 2020). Finally, Sawtooth also produces a Chi-square and relative Chi-square as part of the fit and diagnostic output for each model. The theoretical basis for use of this statistic in model selection is lacking, but Monte Carlo analyses of multiple data sets suggest that it may be useful for model selection – in which case a larger relative chi-square value is desirable. (Orme, 2012)

Additionally, some researchers have argued that class segments should not include fewer than 50 individuals or less than 5% of the total sample (Muthen and Muthen, 2000). However, Weller et al. suggest that segments smaller than 50 can be justified but need to make sense within the conceptual frame of the model (2020). Orme also warns that the data may become “ill-conditioned” if there is not enough information (i.e., the class segments become too small) to estimate all the parameters independently (2012). This is a sign of an ill-fitting model (Orme, 2012)

Attribute importances characterize the relative importance of each attribute compared to the other attributes in the CBC. Stated another way, this is the relative difference each attribute could make in the total utility (or desirability) of a product. Attribute importances are calculated from the part-worth utilities of the levels within each attribute and are used to determine the attribute utility range, which is then divided by the sum of the ranges for all attributes and reported as a percentage of 100. (Orme, 2019)

In addition to attribute importances, part-worth utilities can be calculated for each level. These are numerical scores that measure how much each level contributes to the participant’s perception of the utility or desirability of the attribute or the overall product. Part-worth utilities reported here were zero-centered, meaning that within each attribute the sum of the utilities for all levels will be zero.

To explore the extent of heterogeneity between the two groups in the final model, Fisher’s, chi-square, and t-tests were utilized to determine if there were statistically significant differences based on demographic data. The categorical variables of Gender and Race were evaluated using Fisher’s exact test, while the variables of Hispanic ethnicity and Region of residence in the US were evaluated using chi-square tests. The continuous variable of age was

evaluated using a t-test. Additionally, the classes were assessed for statistically significant differences in previous utilization of mHealth apps for disease self-management (both for cancer as well as any other conditions). These data were collected from the introductory questions of the survey.

The latent class analysis was conducted using Sawtooth Lighthouse 9.12.1 (Sawtooth Software). Frequentist statistics were performed in Microsoft Excel and SAS On Demand (SAS Institute Inc.). All tests for statistically significant differences between the groups were conducted in SAS On Demand.

#### *Institutional review*

This project received the approval of the University of Arizona Institutional Review Board and the University of Arizona Cancer Center Scientific Review Committee.

## **Results**

#### *Respondent demographic characteristics*

Respondents were asked a series of optional demographic questions. For full reporting, see Table 1. The “Prefer not to say” category was not used for any of the questions. Respondents were offered the choice to self-describe their race or ethnicity and one respondent choose this category. Of 110 respondents, 59 reported their gender as female (53.6%), 49 reported their gender as male (44.6%). Only 11.8% of respondents identified as being of Hispanic origin (n = 13). Sixteen respondents identified as Black or African American 82 respondents identified as

White (74.6%). The highest number of respondents identified the region of the US where they reside as South (43, 39.1%), followed by Midwest (24, 21.8%). See Table 5.

Table 5. Respondent demographic characteristics (N =110).

<b>Gender</b>	<b>N</b>	<b>%*</b>
Female	59	53.6
Male	49	44.6
Non-binary/third gender	2	1.8
Prefer not to say	0	0.0
<b>Hispanic</b>		
No	97	88.2
Yes	13	11.8
Prefer not to say	0	0.0
<b>Race/Ethnicity</b>		
American Indian or Alaska Native	5	4.6
Asian	3	2.7
Asian/Black or African American	1	0.9
Black or African American	16	14.6

Native Hawaiian or Other Pacific Islander	2	1.8
White	82	74.6
Prefer to self-describe	1	0.9
<b>Region of the US</b>		
Midwest	24	21.8
Northeast	22	20.0
Other US territory	1	0.1
South	43	39.1
West	20	18.2
Prefer not to say	0	0.0

\*may not add to 100 due to rounding

In addition to the optional demographic questions at the end of the survey, respondents were asked to complete three introductory questions at the beginning. The first question, “Have you used a mobile health app for managing a health condition?”, 53 respondents answered “Yes” (48.2%), 55 answered “No” (50.0%), and 2 respondents answered, “I don’t know” (1.8%). The second question, “Have you used a mobile health app for managing cancer?” saw fewer affirmative responses. Of the respondents, 42 answered “Yes” (38.2%), 66 answered “No” (60.0%), and 2 answered “I don’t know” (1.8%). When asked, “How useful do you think each of the following mobile health app features would be in helping you manage cancer symptoms and treatment?” all app features were rated to be “Very useful” over 60% of the time (range 63.64.0-

72.7%), “Somewhat useful” just under 30% of the time (range 20.9-30.9%), and “Not very useful” less than 10% of the time (range 5.5-8.2%). See Table 6.

Table 6. Respondent ratings of the usefulness of app features prior to choice-based conjoint exercise (N=100).

Attribute	Rating Scale		
	Very Useful n(%)	Somewhat Useful n(%)	Not very useful n(%)
Symptom tracker - record symptoms you experience	70 (63.6)	34 (30.91)	6 (5.45)
Medication tracker - record medications you take	72 (65.5)	32 (29.09)	6 (5.45)
Calendar - keep track of appointments or days you receive treatments	80 (72.7)	23 (20.91)	7 (6.36)
Education - learn about symptom management, treatment side effects, and wellness	70 (63.6)	33 (30.00)	7 (6.36)
Wellbeing tracker – record vital signs, fitness, and nutrition	71 (64.6)	30 (27.27)	9 (8.18)

*Model fit statistics and diagnostics*

The Latent Class analysis provided fit statistics and diagnostics for 2, 3, 4, and 5 group models, see Table 3 The Akaike Information Criterion (AIC) for the 2-group model was highest

at 1353.81, followed by the 3-group model (AIC = 1345.21), the 4-group model (AIC = 1336.67) and the 5-group model (AIC = 1277.03), indicating better fit for the 5-group model. However, the Consistent Akaike Information Criterion and the Bayesian Information Criterion favored the 2-group model (CAIC = 1560.23, BIC = 1525.23). The Relative Chi<sup>2</sup> was lowest for the 5-group model at 3.07, but the 2-group model ranked second-highest at 2.53. The smallest sample segment size for the 2-group model was 44.2%, in the 3-group model it was 13.0%, in the 4-group model it was 10.5%, and finally in the 5-group model it was 9.0%. No model showed a sample segment with less than 5% of the total sample, but the 2-group model came closest to meeting the heuristic of no fewer than 50 persons in each segment. Segments were divided into groups of 61 and 49 participants each. (Muthen and Muthen, 2000) The 2-group model was selected for this Latent Class analysis. See Table 7.

Table 7. Latent class analysis model fit statistics and diagnostics (N = 110).

<b>Fit/Diagnostic</b>	<b>2 groups</b>	<b>3 groups</b>	<b>4 groups</b>	<b>5 groups*</b>
Akaike Information Criterion	1353.81	1345.21	1336.67	1277.03
Consistent Akaike Information Criterion	1560.23	1657.79	1755.41	1801.92
Bayesian Information Criterion	1525.23	1604.79	1684.41	1712.92
Relative Chi-Square	2.53	2.51	2.50	3.07
Average maximum membership probability	0.89692	0.88872	0.90611	0.94399
Number in smallest group	49**	14**	12**	10**
Smallest group % of total sample	44.2%	13.0%	10.5%	9.0%

\*The model for 5 groups displayed the following: “Warning: The data are ill-conditioned.”

\*\*Rounding up to the nearest whole person

Attribute importances vary between the two groups, the most notable difference shown in the importance of the attribute “Medication Tracker” (30.22% for Group 1 versus 15.51% for Group 2). Other major differences include the attributes of “Calendar” (18.32% for Group 1 versus 27.67% for Group 2), “Education” (8.78% for Group 1 versus 16.90% for Group 2), and “Wellbeing” (12.30% versus 8.52%). Only the attribute of “Symptom Tracker” was rated of nearly equal importance to both groups and was rated of highest importance to both groups (30.37% for Group 1 versus 31.40% for Group 2). See Figure 4.

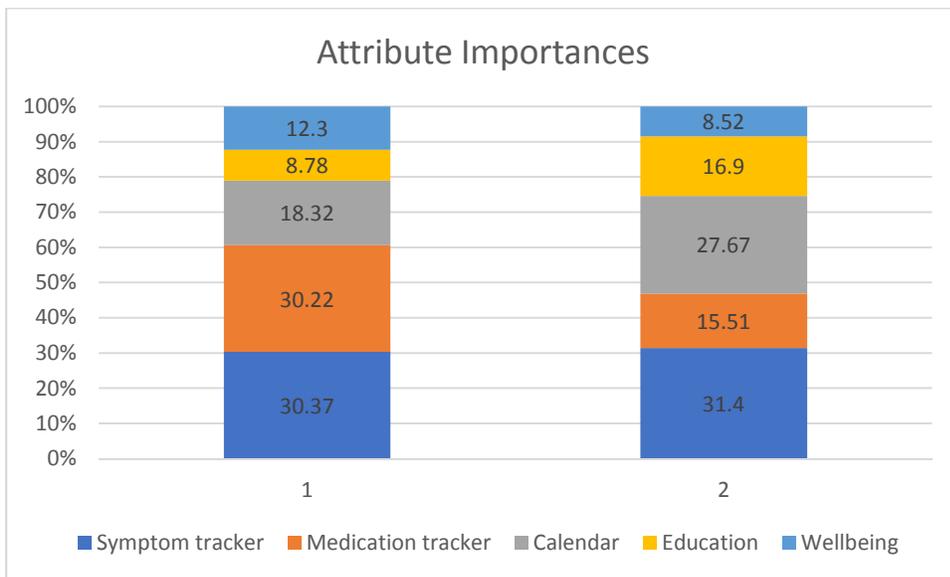


Figure 4. Attribute importances by group (Group 1: n=61; Group 2: m=49).

*Differences in zero-sum utilities by level*

Zero-sum utilities provide the relative utility of each level within an attribute. As the name implies, the utilities listed will sum to zero for each attribute. Though a level may be given a negative utility, it does not necessarily mean that the respondents disliked the level, it just means that the level(s) they gave a positive utility to were preferred. See Table 8 for full results.

### Symptom Tracker

While both groups rated “Symptom Tracker” the attribute of highest importance, the zero-sum utilities are in opposite directions for each level within the attribute. The level of “Automatically alert patient care team based on symptoms” had a utility of 104.72 for Group 1 and -111.52 for Group 2. The level of “Graph symptoms and side effects over time” had a utility of -44.24 for Group 1 and 42.91 for Group 2. The level of “Real-time reporting for symptoms and treatment side effects” had a utility of 21.84 for Group 1 and -14.03 for Group 2. The level of “Weekly reporting for symptoms and treatment side effects” had a utility of -35.18 for Group 1 and 37.15 for Group 2. The level of “Automatically alert patient care team based on symptoms” had a utility of 104.72 for Group 1 and -111.52 for Group 2. And, finally, the level of “Rating of any side effects of health condition or treatments” had a utility of -47.15 for Group 1 and 45.49 for Group 2. All zero-sum utilities for Groups 1 and 2 are presented in Table 4.

### Medication Tracker

Zero-sum utilities for levels within the attribute of “Medication Tracker” ranked in the following order for Group 1: Dose schedule with reminders (66.22), Track when a medication has been taken (60.59), Track when a medication has been delayed or missed (28.75), Graph medication tracking over time (-70.65), and Medication list (-84.90). Zero-sum utilities for Group 2 were as follows: Graph medication tracking over time (54.33), Track when a medication

has been taken (-6.51), Track when a medication has been delayed or missed (-10.46), Medication list (-14.13), Dose schedule with reminders (-23.22). There is clear lack of alignment on the desirability of “Dose schedule with reminders” which is first among the levels for Group 1 and last for Group 2.

### Calendar

Zero-sum utilities for levels within the attribute of “Calendar” were ranked from most favorable to least favorable in the following order for Group 1: Appointment calendar (doctor appointments and treatments) (45.41), Medication dosing schedule with reminders (24.52), Notes and questions for future appointments (-6.39), Appointment reminders (-17.35), Calendar view of medication plan (-46.19). Similarly for Group 2: Appointment reminders (71.30), Appointment calendar (doctor appointments and treatments) (20.49), Medication dosing schedule with reminders (7.62), Calendar view of medication plan (-32.40), Notes and questions for future appointments (-67.02). Both groups viewed “Appointment calendar (doctor appointments and treatments)” and “Medication dosing schedule with reminders” favorably. Additionally, both groups viewed “Calendar view of medication plan” and “Notes and questions for future appointments” less favorably. However, views on the desirability of “Appointment reminders” was mixed.

### Education

Group 1 utilities for levels within the “Education” attribute were ranked in the following order: Social networking and support resources (14.81), Information on side effects appears before a treatment begins (14.28) and Library of symptom resources (-29.09). Meanwhile Group 2 utilities for these levels are ranked as follows: Library of symptom resources (35.96),

Information on side effects appears before a treatment begins (12.58), and Social networking and support resources (-48.54). Both groups had favorable views of “Library of symptom resources”, but opposite views on the desirability of the remaining two levels.

Wellbeing

The utilities for the levels of the attribute “Wellbeing” were ranked as follows for Group 1: Fitness tracking (upload information from fitness device, step counter) (30.90), Graph fitness and nutrition trends over time (27.25), Rating of general wellness (-27.55), and Weight tracking (-30.59). Similarly, for Group 2: Graph fitness and nutrition trends over time (16.44), Weight tracking (9.41), Fitness tracking (upload information from fitness device, step counter) (0.32), and Rating of general wellness (-26.17). While both groups had less favorable views of “Rating of general wellness”, the desirability of the remaining levels was mixed between the groups.

Table 8. Latent class analysis zero-sum utilities for levels by group.

<i>Attributes</i>	<i>Zero-sum Utilities*</i>	
	Group 1 n=61	Group2 n=49
<b>Symptom tracker</b>		
Graph symptoms and side effects over time	-44.24	42.91
Real-time reporting for symptoms and treatment side effects	21.84	-14.03
Weekly reporting for symptoms and treatment side effects	-35.18	37.15
Automatically alert patient care team based on symptoms	104.72	-111.52
Rating of any side effects of health condition or treatments	-47.15	45.49

<b>Medication tracker</b>		
Dose schedule with reminders	66.22	-23.22
Graph medication tracking over time	-70.65	54.33
Medication list	-84.9	-14.13
Track when a medication has been taken	60.59	-6.51
Track when a medication has been delayed or missed	28.75	-10.46
<b>Calendar</b>		
Medication dosing schedule with reminders	24.52	7.62
Appointment reminders	-17.35	71.3
Notes and questions for future appointments	-6.39	-67.02
Appointment calendar (doctor appointments and treatments)	45.41	20.49
Calendar view of medication plan	-46.19	-32.4
<b>Education</b>		
Social networking and support resources	14.81	-48.54
Library of symptom resources	-29.09	35.96
Information on side effects appears before a treatment begins	14.28	12.58
<b>Wellbeing</b>		
Fitness tracking (upload information from fitness device, step counter)	30.9	0.32
Weight tracking	-30.59	9.41
Graph fitness and nutrition trends over time	27.25	16.44
Rating of general wellness	-27.55	-26.17

\*sum of the utilities for all levels will be zero

### *Demographic characteristics of respondents by preference pattern*

There was a statistically significant difference between the groups when looking at respondents who answered “Yes” to the question, “Are you of Hispanic, Latino, or Spanish origin?” Group 1 had 13 affirmative responses and Group had zero. This resulted in a Chi square score of 11.84 ( $p = 0.0006$ ). There was no statistically significant difference between groups for the demographics of gender (Fisher’s  $= 0.04$ ,  $p = 0.53$ ), age (t test = -1.32,  $p = 0.19$ ), race (Fisher’s  $= 0.00$ ,  $p = 1.00$ ), or region of residence in the US (Chi square = 7.78,  $p = 0.10$ ). There were no statistically significant differences between groups based on previous use of an mHealth app (Chi square = 1.77,  $p = 0.41$ ), or previous use of an mHealth app for cancer (Chi square = 3.11,  $p = 0.21$ ).

### **Discussion**

Our study explored discrete choice methods to understand patient preferences for features of cancer self-management mHealth apps. Implementation of a survey containing a choice-based conjoint exercise showed contrasts in respondent preferences depending on question format. In addition, latent class analysis revealed evidence for a two-group model. Finally, we explore the evidence for validity of the attributes and levels of the choice-based conjoint survey as well as the latent content analysis model.

Respondent’s estimation of the usefulness of attributes presented in the survey differed depending on the format of the question. Our survey incorporated both a rating scale question and a choice-based conjoint exercise to estimate patient preferences for mHealth app attributes. In the rating scale question in the introduction of the survey, “Calendar” was the attribute which

received the highest percentage of respondents reporting that the attribute was “Very useful” (n = 80, 72.7%) while “Symptom tracker” was rated lowest (tied with “Education”), as only 70 respondents (63.6%) considered this attribute “Very useful”. However, in the LCA both groups 1 and 2 indicated the highest preference for the “Symptom tracker” attribute (in Group 1 this accounted for 30.4% of total attribute importances and in Group 2 it accounted for 31.4%). Thus, expressed patient preferences may vary with question format. One reason for this may be patient understanding of the question being asked. Pearce et al. (2021) conducted an extensive literature review of discrete choice studies showing that how patient understanding of questions can vary widely. There is a lack of consensus on the appropriate methodology for ensuring that patients understand both attributes/levels as well as choice tasks.

The literature reveals heterogeneity regarding the methodology utilized to assess patient preferences for chronic disease self-management apps. While examples of discrete choice or choice-based conjoint studies to explore patient preferences in apps for diseases self-management were not identified in our search of the literature (Vaffis et al., 2022), several examples can be found that used a rating scale approach. Conway et al. (2016) utilized an online questionnaire to explore patient preferences for a diabetes app. The survey contained 39 items and used a 5-point response scale (I would use... agree/disagree). Seventeen app features were assessed, many of which were exclusive to diabetes management (such as glucose tracking). Geuens et al. (2019) interviewed patients to evaluate 28 app features for managing chronic arthritis. Patients were asked to rate app features using a 5-point Likert scale (strong dislike to strong like). Though not reporting the use of a rating scale approach, an app development study by Tran et al. (2020) included a discussion of patient input on app features. Patients indicated preferences for emotional and well-being support over symptom reporting, suggested

incorporating online communities of support (such as Facebook or Reddit), and requested data summary features to help track information they were inputting over time.

The results of the Conway et al. (2016), Geuens et al. (2019) and Tran et al. (2020) studies can be compared to our results. Of those features also explored in our study, Conway et al.'s (2016) results indicated that graphic display/analysis was ranked second most preferable while "Physiology tracker" and "Weight tracker" (similar to the "Wellbeing" attribute in this study) were ranked in the middle (Physiology was ranked 8<sup>th</sup> most preferable and Weight was 10<sup>th</sup> most preferable). Reminders and alarms were 4<sup>th</sup> lowest (14<sup>th</sup>) and social media integration was ranked lowest (17<sup>th</sup>). These results are similar to our rating scale question in which "Wellbeing" and "Education" received middle ranking, as well as our LCA results which showed lower preferences for the "Wellbeing" and "Education" attributes. The Geuens et al. (2019) study in chronic arthritis found that logs for reporting, medication reminders, and disease tracking were among the five most preferred attributes while social comparison, social media, and social identification were among the five least preferred. These are like the results seen in our LCA where "Symptom tracker" and "Medication tracker" were of higher importance than "Education" but are in contrast to the results of our rating scale question in which these attributes were ranked lowest. In comparison to Tran et al. (2020), which found X and Y, participants in our study Group 1 gave lowest preference to "Education" (which included the level of online support) and Group 2 gave it second-lowest preference. Within this attribute, Group 1 had positive utility values for the level of online support, Group 2 did not. Group 2 gave positive utilities the levels for graphing symptoms and medication use over time, while Group 1 gave both levels negative utilities. It is important to note that negative utility values do not necessarily indicate that respondents do not like the levels receiving negative utilities, rather that all things

being equal they prefer another level more. (Orme, 2019) Thus, the results of our study suggest future research in the areas of best-practices for both methodology and reporting in app development are called for. Furthermore, use of discrete choice methods for establishing patient preferences may lead to greater comparability across studies. Reporting of the utilities could lead to more nuanced understanding of what is valuable across the population of cancer patients as well as to subpopulations with common diagnoses.

The LCA revealed only one statistically significant difference between Groups 1 and 2. Respondents who identified as Hispanic, Latino, or of Spanish origin (n = 13) were all in Group 1. This finding is reminiscent of differences that have been observed in Likert scale survey response patterns of those who identify as Hispanic and non-Hispanic (Hui and Triandis, 1989; Mirin et al., 1992) which indicated that response patterns of Hispanics are distinct from non-Hispanics and trend toward affirmation. To the authors knowledge there are no studies exploring differences in response patterns between these two groups in conjoint analysis. However, the difference in response patterns observed here warrants further research.

The objective of this formative research was to demonstrate instrument validity and feasibility in the cancer patient population through expert opinion, patient focus groups, and pilot testing. Content validity was established through testing attributes and levels with experts in app development, communications with cancer patients, and cancer clinical care. Furthermore, model validity for the LCA was established through goodness of fit statistics and diagnostic statistics. Further establishment of reliability evidence could be produced through test-retest of respondents, though lack of available funding prohibited such measures in this study. Future research could seek to establish evidence for reliability of the attributes and levels selected in this

study through test-retest and evidence for validity through cognitive debriefing with respondents to determine their agreement with the selection of attributes and levels.

### *Limitations*

Our study has limitations. Self-reported data have long been shown to contain bias. The utilization of self-report data here requires results to be interpreted with caution. Additionally, the small sample size may present skewed results, especially within the latent class analysis. Weller et al. (2020) suggest that 300 participants is the minimum for LCA but do agree that smaller samples are sufficient for more parsimonious models (those with fewer indicators and classes). Nylund et al., suggest that in samples lower than 200 Information Criterion and likelihood-tests may not accurately identify the correct model (2008). Finally, regarding categorical variables, categories with less than 10% of the sample could be collapsed. This cut-off is arbitrary according to Sinha et al. (2020). Though this was a nationally collected sample, the sample size may impact generalizability.

### **Conclusions**

Choice-based conjoint exercises and latent class analysis may be useful tools in exploring patient preferences for the features and functions of mHealth apps that aid in cancer self-management – both during the app development and updating stages. Further research into best-practices for both methodology and reporting may help align results across studies so that differences in patient preferences for mHealth app features will be comparable.

## **Chapter 6: DISCUSSION AND CONCLUSIONS**

The purpose of this project was to explore whether discrete choice methods, such as a choice-based conjoint exercise, could be applied to discern patient preferences for the features of mHealth cancer apps for disease self-management. While the major portions of this work were hypothesis generating, we did set the following hypothesis:

*There is no difference in the relevance of attributes and levels for features of cancer self-management mHealth apps with respect to patient preferences.*

To generate evidence to test this hypothesis, four research objectives were set.

### *Objective 1*

To characterize key features and functions that influence cancer patient preference for mHealth apps using a scoping review of the literature

### *Objective 2*

To characterize key features and functions that influence cancer patient preference for mHealth apps using subject matter expert opinion collected through a Delphi method survey

### *Objective 3*

To create a discrete choice survey instrument and to assess validity and reliability in the cancer patient population

#### *Objective 4*

To quantitatively determine cancer patients' preferred app design

To achieve these objectives, the research was segmented into three distinct phases. First was a scoping literature review to discover how mHealth cancer self-management apps were described in the literature, including key features and functions. Second, a survey was developed for experts in the fields of cancer app development, communications with cancer patients, and cancer clinical care. The purpose of the survey was to characterize the key app features and functions uncovered in the preceding scoping literature review according to the experts' determination of their relevance to cancer patients. The results of the survey were translated into attributes and levels that could be employed in a discrete choice experiment. Finally, a survey was developed for cancer patients and survivors to learn what mHealth app features and functions cancer patients preferred for disease self-management.

### **Scoping literature review**

#### *Methods*

As the purpose of this study was to explore the depth and breadth of research on mHealth app features for cancer self-management, a scoping review methodology was adopted for this

study. Four databases were used for this review: PubMed/MEDLINE, EMBASE, CINAHL, and PsycINFO. Citation and reference searches were conducted for manuscripts meeting the inclusion criteria. A gray literature search was also conducted. Data extracted from manuscripts included: author; title, publication date; study type; sampling type; cancer type; treatment; age of participants; features; availability (free or subscription); design input; and patient preferences. Finally, the features listed for each app were compared, highlighting similarities across platforms as well as features unique to each app.

### *Key findings*

In total, seven studies published from 2017 to 2021 were included for analysis. Studies varied in methodology, from descriptive to experimental, and size, with subject sizes ranging from 11 to 218. Additionally, apps were developed to address the needs of a heterogeneous patient population; some address the needs of a single cancer indication or treatment, and others provide support across the spectrum of cancer diagnoses. Likewise, the number of features per app varied from two to eleven with a median of four – with the most reported feature being a symptom tracker. Lastly, several studies reported patient acceptability or preference data for the app and/or the features with acceptability (assessed through survey or interviews) most frequently reported.

Popular features within these mHealth apps include symptom trackers, cancer education, and medication trackers. However, these apps and features are often developed with little input from patients. Additionally, there is little information regarding patient preferences for the features of existing apps.

## **Expert opinion survey**

### *Methods*

The 40 app features identified in the scoping literature review were collated into groups according to their function. For example, medication tracking features were collated into a single group. This resulted in nine groups and these groups formed the basis of questions for the expert opinion survey. The nine groups were: landing page, tracking symptoms, medication adherence and/or tracking, education and news, calendars and planning, reminders, wellbeing and emotional/social support, physical fitness and nutrition, and tools and settings.

An online survey was developed with one question for each group of app features listed above. Participants were asked to endorse each feature deemed useful for patients in cancer self-management. After each question respondents were asked to contribute additional app features related to that group which might also be useful to patients. The data were analyzed to determine the attributes with the highest relevance for mHealth apps for cancer patients according to the subject matter experts (as measured by lowest composite score when a rating of 9 out of 9 is the most relevant).

### *Key findings*

The data resulting from this survey of experts were unexpectedly homogenous given their differing fields of practice. A total of nine experts responded to the survey. Only two questions included features that were not endorsed by seven or more participants. Question 7 had two

features not selected by seven or more participants (Journaling and Healthy doses) and Question 9 had one feature not selected by seven or more participants (Notices of privacy and data usage). Each category of features was accompanied by an open-ended question allowing the respondents to introduce features not identified in the literature. Through these options were only used twice, one new feature did appear “reminders to refill ongoing prescriptions based on 30/90 day supply”.

A more diverse range of endorsements was anticipated within and across categories. Whereas the expert panel might have been expected to rate the categories of “Medication adherence and/or tracking” or “Tracking symptoms” most highly, the highest rated categories were “Calendars and planning” and “Physical fitness and nutrition”. These results are counter-intuitive given the shown association between lower costs and improved quality of life and increased use of mHealth apps for medication adherence and symptom and/or side-effect monitoring. Furthermore, “Landing page” or “Tools and settings” categories might have expected to rank toward the bottom, the category of “Wellbeing and emotional/social support” was ranked lowest by the experts. This may suggest that the option for mHealth apps to support patients’ needs beyond strictly medical concerns was of less importance to the experts compared to patient education and medication adherence or may indicate that the list of features identified in the literature were deemed unsuitable to meet patient’s needs. Without the use of the open-ended questions to introduce features more appropriate to this category it might be the case that the experts valued this category lowest regardless of the features available.

### **Patient choice-based conjoint survey and latent class analysis**

## *Methods*

A survey containing a choice-based conjoint exercise was utilized to reveal patient preferences for the features we previously identified in mHealth apps in the literature. The discrete choice experiment was designed as a choice-based conjoint exercise in Lighthouse Studio 9.12.1 (Sawtooth Software). The choice exercise consisted of nine choice tasks in which respondents compared the features of hypothetical mHealth apps for cancer self-management. This analysis utilized a latent class multinomial logit model to identify different segments (groups) of respondents based on response patterns. The survey also contained five demographic questions which enabled testing for significant differences between the groups identified in the latent class analysis.

## *Key findings*

The survey showed contrasts in respondent preferences depending on question format. In addition, latent class analysis revealed evidence for a two-group model. Finally, evidence for validity of the attributes and levels of the choice-based conjoint survey as well as the latent content analysis model was analyzed.

Respondent's estimation of the usefulness of attributes presented in the survey differed depending on the format of the question. The survey incorporated both a rating scale question and a choice-based conjoint exercise to estimate patient preferences for mHealth app attributes. In the rating scale question in the introduction of the survey, "Calendar" was the attribute which received the highest percentage of respondents reporting that the attribute was "Very useful" (n = 80, 72.7%) while "Symptom tracker" was rated lowest (tied with "Education"), as only 70

respondents (63.6%) considered this attribute “Very useful”. However, in the LCA both groups 1 and 2 indicated the highest preference for the “Symptom tracker” attribute (in Group 1 this accounted for 30.4% of total attribute importances and in Group 2 it accounted for 31.4%). Thus, expressed patient preferences may vary with question format. One reason for this may be patient understanding of the question being asked. There is a lack of consensus on the appropriate methodology for ensuring that patients understand both attributes/levels as well as choice tasks.

The latent class analysis revealed only one statistically significant difference between Groups 1 and 2. Respondents who identified as Hispanic, Latino, or of Spanish origin (n = 13) were all in Group 1. This finding is reminiscent of differences that have been observed in Likert scale survey response patterns of those who identify as Hispanic and non-Hispanic which indicated that response patterns of Hispanics are distinct from non-Hispanics and trend toward affirmation/endorsement.

### **Overall limitations**

The literature review was scoping in nature so a quality assessment wasn’t conducted for the studies meeting the inclusion criteria, which can limit the depth of understanding about these studies. Additionally, this study specifically sought information on smartphone and tablet apps. This meant a narrow range of inclusion dates was used to account for current smartphone operating systems.

The main limitation of the expert opinion survey was the use of a convenience sample. An effort was made to be inclusive of the fields of expertise involved in the development of mHealth apps, but there’s no getting around the fact it was a small sample.

The patient survey relied on self-reported data, which has a long-established history of bias (CITE). In addition, while early research in latent content analysis used fewer attributes and levels with a smaller sample size (similar to this study), more recent work has suggested larger samples are needed. Some researchers (Weller et al, 2020) agree that smaller samples are sufficient for more parsimonious models (those with fewer indicators and classes). But there is evidence (Nylund et al.,2008) that in samples lower than 200 Information Criterion and likelihood-tests may not accurately identify the correct model. Regarding categorical variables, categories with less than 10% of the sample could be collapsed – but this cut-off is noted to be arbitrary (Sinha et al., 2020). Finally, though this was a nationally collected sample, the sample size may impact generalizability.

## **Conclusions**

The objectives of this formative research were to demonstrate whether discrete choice methods were fit-for-purpose in determining patient preferences for mHealth app features through expert opinion and patient surveys. The choice-based conjoint patient survey revealed there are differences between patient groups for preferred app features. Based on these outcomes, we are able to reject the null hypothesis that there is no difference in patient preferences for features of mHealth apps for cancer self-management.

However, the scoping literature review demonstrated that hundreds of mHealth apps exist for varied purposes spanning the cancer continuum, from cancer prevention and detection to palliative care and survivorship. Patient preferences for app features are likely to vary based on the primary function of an app (i.e., skin cancer diagnosis versus recovery post-surgery).

There are findings from this research that warrant further exploration. When asked with a rating question how useful app features would be, both experts and patients selected “Calendars and planning” (in the expert survey) or “Calendar” (in the patient survey). This differed from the outcome of the choice-based conjoint exercise in which both groups of patients in the latent class analysis model rated “Symptom tracker” as the attribute of highest importance. More research is needed to define methodologies best fit for purpose in understanding patient preferences.

## Appendices

### Appendix A. EXPERT SURVEY

Page 1 of web survey

#### **Introduction statement**

This research study seeks to better understand cancer patient preferences for mobile health apps to aid in disease self-management.

Mobile health (mHealth) is the use of smart devices (such as tablets and phones) to support healthcare delivery.

We conducted a literature review of studies that tested mHealth apps. We identified features (such as calendars or medication trackers) that currently exist in these mHealth apps.

You will be asked to select all the features you think would be useful to cancer patients in disease self-management. In addition, there will be an open field for you to include features you believe would be useful to patients that were not identified in the literature.

The total time commitment should be minimal (10-15 minutes).

Page 2 of web survey

#### **Survey instructions**

Each question lists a group of related mHealth app features identified in the literature (for example, a number of studies noted mHealth apps which included symptom trackers). Though the features are related, there may be slight variations in their functionality. Please select **ALL** features from the list that would be useful to patients (which may mean selecting more than one symptom tracker, etc.).

Page 3 of web survey

**Question 1** – The following mHealth app features were identified in the literature and relate to the **landing page** (first page viewed on app).

Please select **ALL** the app features from the following list that would be useful to patients.

Homepage (contains the following links: Overview, Local resources, Treatments, Day-to-day matters, Health and wellbeing, Social support, Emotional support, Favorites, Settings)	
Welcome screens (explain study purpose and how to use app)	
Homepage (medication treatment plan and suggested healthy recipes)	

Please include any additional features related to the **landing page** that would be useful to patients here:

--

Page 4 of web survey

**Question 2** – The following mHealth app features relate to **tracking symptoms**.

Please select **ALL** the app features from the following list that would be useful to patients.

Management and reporting of side effects (with integral patient decision support system to call nurse at cancer clinic, if needed, summary of all side effects registered in each treatment cycle)	
Symptom tracker (documentation of and rating of their general wellness or whether they are experiencing any side effects of their health condition or treatments; a graph is generated to show trends over time)	

Symptom reporting trends (graphical display of weekly symptom trends, customized for each patient and their medical oncologist)	
Symptom reporting (weekly and real-time symptom reporting for common symptoms and treatment side effects, with algorithms that personalize symptom management suggestions or enable participants to call their care team directly from the app)	
Symptom assessment (validated health-related quality of life surveys relevant to prostate cancer completed once per week)	
Adherence and symptom reporting module	

Please include any additional features related to **tracking symptoms** that would be useful to patients here:

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Page 5 of web survey

**Question 3** – The following mHealth app features relate to **medication adherence and/or tracking**.

Please select **ALL** the app features from the following list that would be useful to patients.

Medication tracker (adding medications to the list, set reminders, and document when a medication has been taken, postponed, or missed, and the reasons why)	
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Adherence and symptom reporting module	
--	--

Please include any additional features related to **medication adherence and/or tracking** that would be useful to patients here:

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Page 6 of web survey

**Question 4** – The following mHealth app features were identified in the literature and relate to **education and news**.

Please select **ALL** the app features from the following list that would be useful to patients.

Patient education (for symptom management and other cancer-related topics)	
Education library (symptom management, social networking, and support resources, nutrition, and clinical contact information)	
Resource view (resources appear one week before a new treatment, or at the end of a treatment, to help a patient learn what to expect and prepare for this change)	
Information recommendations (each user profile includes all treatments and treatment dates. These dates signal a transitional event that generates recommendations based on the patient’s treatment path)	

User Survey (may be completed at any time to immediately receive information related to current questions or challenges; information is pulled from a database of over 300 information resources from American Cancer Society, breastcancer.org, and cancer.net)	
Medical information (information on oral cancer, oral cancer treatment, hospice care, other supporting personnel, or cancer treatment institutions)	
Latest news (latest communications to patients after surgery, links to YouTube videos on oral health education and health and neck rehabilitation, links to patient groups through LINE app)	

Please include any additional features related to **education and news** that would be useful to patients here:

--

Page 7 of web survey

**Question 5** – The following mHealth app features were identified in the literature and relate to **calendars and planning**.

Please select **ALL** the app features from the following list that would be useful to patients.

Supporting adherence to medication (calendar view of medication plan, alerts, and reminders for dose schedule)	
Personalized medication dosing schedule (with optional reminders)	

Appointment calendar (tracking of all doctor appointments and treatments)	
To-do list (allows users to make a list of tasks that need to be completed)	
Notes and questions (store notes and questions for future clinical visits)	

Please include any additional features related to **calendars and planning** that would be useful to patients here:

--

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**Question 6** – The following mHealth app features were identified in the literature and relate to **reminders**.

Please select **ALL** the app features from the following list that would be useful to patients.

Revisit reminders (provides a reminder function for patients to remember to return to the hospital)	
Reminders to complete survey/track symptoms (optional)	
Personalized medication dosing schedule (with optional reminders)	

Medication tracker (adding medications to the list, set reminders, and document when a medication has been taken, postponed, or missed, and the reasons why)	
Supporting adherence to medication (calendar view of medication plan, alerts, and reminders for dose schedule)	

Please include any additional features related to **reminders** that would be useful to patients here:

--

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**Question 7** – The following mHealth app features were identified in the literature and relate to **wellbeing and emotional/social support**.

Please select **ALL** the app features from the following list that would be useful to patients.

Healthy doses (library of motivational and inspirational quotes with images on the topics of gratitude, optimism, love, humor, and mindfulness)	
Journaling (list of guided topics, such as what am I thankful for today, and a free writing space to journal about any topic)	
Daily mood diary (tracking daily moods from a collection of 11 positive and 11 negative emotional identifiers, adapted from PANAS [Positive and Negative Affect Schedule] mood scale)	

Circles of support (adding any person to view activities or progress tracked on the app as directed by user)	

Please include any additional features related to **wellbeing and emotional/social support** that would be useful to patients here:

--

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**Question 8** – The following mHealth app features were identified in the literature and relate to **physical fitness and nutrition**.

Please select **ALL** the app features from the following list that would be useful to patients.

Wearable fitness tracking device (stream data from Fitbit devices to app, display daily step counts, and allow users to set daily step goals and display progress towards those steps)	
Fitbit integration (for tracking physical activity)	
Weight tracking (tracking of weight and the ability to generate a graph over time for trends)	
Vital sign tracker (tracking of common vital signs such as pulse and blood pressure and the ability to graph trends over time)	

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Please include any additional features related to **physical fitness and nutrition** that would be useful to patients here:

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**Question 9** –The following mHealth app features were identified in the literature and relate to **tools and settings**.

Please select **ALL** the app features from the following list that would be useful to patients.

Self-recording (enables patients to record their own postoperative information and symptoms e.g., date, body temperature, pain level, oral ulcer, vomiting, skin reactions, diarrhea)	
Notes and questions (store notes and questions for future clinical visits)	
Tool library (additional set of mini-apps that users can browse and pull into their home screen based on their preferences; the categories within the tool library consist of organization and reminder, tracking and monitoring, nutrition, and physical activity)	
Notices of privacy and data usage	

Please include any additional features related to **tools and settings** that would be useful to patients here:

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Thank you for your participation in this project. If you have any questions, please contact Shannon Vaffis via email at [vaffis@pharmacy.arizona.edu](mailto:vaffis@pharmacy.arizona.edu).

## Appendix B. PATIENT SURVEY WITH CHOICE-BASED CONJOINT EXERCISE PROGRAMMING

Are you at least 18 years of age?

Yes

No

---

Have you ever had cancer?

Yes

No

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[Informed Consent.pdf](https://svua.qualtrics.com/CP/File.php?F=F_4ZaY7oEqymqDNik) Please review the attached Informed Consent Form before proceeding with the survey.

I agree to participate in this survey.

I do NOT agree to participate in this survey.

---

This survey will ask questions about your use of technology to manage cancer (tracking symptoms and medications, getting information about treatments, etc.).

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A mobile health app can be downloaded to a smartphone or tablet.

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First we have a couple of questions about your use of mobile health apps.



Page Break



Have you used a mobile health app for managing a health condition?

Yes

No

I don't know

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Page Break

Have you used a mobile health app for managing cancer?

Yes

No

I don't know

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Page Break

How useful do you think each of the following mobile health app features would be in helping you manage cancer symptoms and treatment?

	Very useful	Somewhat useful	Not very useful
Symptom tracker - record symptoms you experience			
Medication tracker - record medications you take			
Calendar - keep track of appointments or days you receive treatments			
Education - learn about symptom management, treatment side effects, and wellness			
Wellbeing tracker - record vital signs, fitness, and nutrition			

## Start of Block: ConjointBlock

(1/9) Choose the group of features you prefer by clicking on Option 1 or Option 2.<br><br>

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End of Block: ConjointBlock

Please tell us about you.

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Page Break

What is your age?

Enter age, in years \_\_\_\_\_

Prefer not to answer

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Page Break

With which gender do you identify?

Male

Female

Non-binary / third gender

Prefer to self-describe \_\_\_\_\_

Prefer not to answer

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Page Break

Are you of Hispanic, Latino, or Spanish origin?

Yes

No

Prefer not to answer

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Page Break

With which race/ethnicity do you identify?<div>Choose all that apply.</div>

American Indian or Alaska Native

Asian

Black or African American

Hawaiian Native or Other Pacific Islander

White

Prefer to self-describe \_\_\_\_\_

Prefer not to answer



Page Break

In which region of the country do you live?

Midwest (IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, SD, WI)

Northeast (CT, DC, DE, MA, MD, ME, NH, NJ, NY, PA, RI, VT)

South (AL, AR, FL, GA, KY, LA, MS, OK, NC, SC, TN, TX, VA, WV)

West (AK, AZ, CA, CO, HI, ID, NM, NV, UT, WA, WY)

Other US territory

Prefer not to answer

End of Block: Block 2

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