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Final Report

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Canada Drug Guide: A Pilot Study (NA 204)
Final Report

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EXECUTIVE SUMMARY

Canada Drug Guide Project: A Pilot Study (NA 204)

Overview:

The Canada Drug Guide pilot study represents one of the largest and most extensive evaluations of patient-oriented therapeutic information ever done in Canada.

Purpose of Study:

The main purpose of this study was to:

- test the feasibility of producing evidence-based therapeutic guides in lay language; and,
- assess the acceptability, utility and impact of these guides on physicians, pharmacists and consumers.

Target Audience:

The target audience of this report is broad. The findings are applicable to drug policy makers, program evaluators, academic researchers, physicians, pharmacists and consumers. Health and patient educators, as well as those interested in consumer drug information, health promotion or health education research may also find this report of interest.

Methodology:

This project developed and tested evidence-based therapeutic guides as part of a two year national pilot project. The research was designed to see how patients and clinicians would use simple therapeutic guides in the course of an interaction, and to measure what kind of impact, if any, these would have on the nature and outcome of the interaction.

Our first objective was to assess the current literature on evaluations of patient-oriented drug information and survey current patient-oriented drug information available in Canada. We proceeded to establish an understanding of the drug information needs of patients through systematic qualitative assessments (focus groups), with patients, physicians, and pharmacists in three regions of Canada. Prototype guides were developed around three sentinel conditions (osteoporosis, sore throat and GERD or heartburn) with input from the focus group participants.

We enrolled 53 physicians and 30 pharmacists in three Canadian cities (Halifax, Hamilton and Vancouver) to disseminate and discuss our patient-oriented drug therapy guides in the course of their typical consultations. We evaluated patients' perceptions of the usefulness and influence of this information through structured telephone interviews. In total, feedback from 1176 patient telephone interviews was received. Chart audits were conducted in the offices of the participating physicians to assess the effect of the guides on prescribing and subsequent patient care. Chart data on guide users was compared to a set of control charts based on patients who fit the enrollment criteria, but did not use the guides. A web-based version of the osteoporosis guide was also evaluated by a group of seniors using an internet questionnaire. The study was concluded with exit interviews with the participating clinicians to determine how the guides were actually used in the clinical setting.

Main Findings:

- The Canada Drug Guide pilot study successfully produced and evaluated three separate disease oriented, evidence-based drug information guides with physicians, pharmacists and consumers across Canada. (these can be found at www.canadadrugguide.org)
- Patients reported wanting information about all treatment options, including information about why a drug prescription is deemed necessary. They also wanted information of a drug's side effects, appropriateness, duration of therapy and costs.
- Most participants in the internet survey (83%) expressed a wish to have electronic access to other Canada Drug Guides in the future.
- Physicians and pharmacists expressed concern about the amount of information patients said they needed. Some clinicians believe that the amount of side effect and safety information that they give out to their patients should be limited.
- Between 80-90% of patients using the guides found them easy to understand; 48-60% of patients reported that the guides had a "moderate" to "very large" influence on their decision making.
- 98% of physicians and 92% of pharmacists reported that the information guides helped their patients understand the issues involved in their treatment.
- 53% of physicians involved in the study thought the information guides would have an impact on the drug they chose to select for their patients.
- Analysis of chart audit data revealed that the use of the guides had a significant impact on the type of counseling patients received (as reflected by the chart notes) in the treatment of sore throat and heartburn, especially with respect to 'other' or non-drug measures to control and treat symptoms.
- Among those women who consulted their physicians for information on the prevention or treatment of osteoporosis, guide users were less likely to use a bisphosphonate and more likely to use hormone therapy than the control patients who did not receive a guide. (This data has not yet been adjusted for potential confounders so it is premature to make inferences regarding the impact of the osteoporosis guide until a comprehensive analysis is completed.)

Recommendations and Policy Implications
(as applicable to creators and disseminators of drug information)

- Patients and clinicians want access to a readily available, evidence-based and user-friendly drug information tool that is easily updated.
- Evidence based information plays an important role in the decision making process.
- Patients will better absorb drug information if it is provided in a meaningful context, particularly if the context includes relevant information about their disease or condition.
- Drug information research must involve the users of the information and must be integrated into the present realities of the doctor-patient-pharmacist interaction
- More research into the impacts of objective drug information on health outcomes has to be done.

PURPOSE AND RELEVANCE OF THE PROJECT

Purpose:

The main purpose of this study was to:

1) test the feasibility of producing evidence-based therapeutic guides for patient use; and,
2) assess the acceptability, utility and impact of these guides on physicians, pharmacists and patients.

One of the major health transitions currently underway is a greater involvement of patients in their treatment decision-making.[1] Accordingly, patients need and want more information about their medications and non-drug therapies. However, the process of enabling patients to improve their treatment decision-making by supplying them with information, often called "information therapy," has not been well studied.[2] The increase in the number of prescription drugs available to consumers and the influence of commercial or professional interests can bias the material available to consumers.[3] As well, the increasing investment being made by drug manufacturers in direct-to-consumer advertising of pharmaceuticals in the United States adds to the drug misinformation problem in Canada.[4]

There is, therefore, a need for an independent, authoritative national drug decision-making guide for lay people that will be easily accessible to patients when they need it.[5] The Canada Drug Guide Project sought to develop and test information guides for three common medical conditions, with the intention that these guides could later serve as prototypes in the development of a comprehensive patient-oriented therapeutic guide.

The research project involved **three** distinct phases:

1. **Analysis of evaluations of patient-oriented drug information and survey of patient-oriented drug information currently available in Canada** (Appendix A).

2. **Development and testing of treatment guide prototypes targeted at three distinct types of medical condition**: sore throat (acute symptomatic), osteoporosis (chronic asymptomatic) and heartburn (chronic symptomatic). This phase of the project involved reviewing available therapeutic evidence, as well as conducting focus groups with patients, physicians, and pharmacists in three provinces (British Columbia, Nova Scotia, and Ontario).
The focus groups helped determine the general treatment information needs of patients, as well as those that were particular to these three medical conditions. A semi-structured interview guide consisting of open-ended questions was used to gather data (Appendix B). The three main objectives of the focus groups were:
   - to determine what patients want to know about the medications they are taking;
   - to determine the best format and method of delivery of medication-related information to patients; and,
   - To determine physician and pharmacist comfort and acceptance of the suggestions/ideas proposed by patients.

3. **Evaluation of the three treatment guides in clinical settings.** Other than a short evaluation of the osteoporosis guide as distributed over the Internet, the crux of the evaluation came from the use of our guides by patients in the offices of family physicians or in community pharmacies. (Copies of the three guides can be found in Appendix C) The

evaluation of the guides in clinical settings was designed to achieve the following:

- to determine and measure patients' experience with the guides and their subsequent decisions regarding treatment;
- to determine the effectiveness of this method of delivering the guides to patients; and,
- to determine whether the guides, when distributed in a clinical setting and used as part of a visit with a health professional, are useful and if it contributes to therapeutic decision-making, and;
- To determine whether the guides have an impact on prescribing or on the patient's subsequent care.

Relevance:

This study is of particular relevance to policymakers, health decision-makers, health educators and health care practitioners. With patients becoming increasingly eager to be fully informed about their treatment options, including alternatives to treatment and non-drug therapies, many health professionals believe they should have a direct role in providing that information. Enhanced verbal or written communications to patients regarding pharmaceuticals are likely to be in great demand in the future, especially where it can be shown that providing that information leads to beneficial health impacts or a more efficient use of resources. As drug budgets continue to be one of the fastest growing segments of the health care system, patient understanding of the effectiveness, risks and benefits of medications will be increasingly important.

Data regarding public education in rational drug use are rarely published or fully documented .[6] This project was intended to help fill that gap, by measuring and documenting the impact consumer-oriented drug information has on patient therapeutic decision-making and subsequent drug use.

PROJECT ACTIVITIES

This section describes the process of evaluating the guides by patient interview and chart audit in the clinical setting. Appendix D provides a complete description of the focus group methodology, design and activities.

Methodology

Family physicians and community pharmacists in Ontario (Ancaster, Dundas, Hamilton, Stoney Creek, and Waterdown), Nova Scotia (Halifax, Dartmouth, Bedford, Fall River, and Berwick) and British Columbia (Vancouver, Langford, Tswassen, and Coquitlam) were asked to participate in the study. Overall, 53 physicians and 30 pharmacies participated in the study.

These sites were asked to recruit patients who presented with, or were interested in receiving information about, one of the three target conditions (sore throat, heartburn, or osteoporosis). Patients were restricted to only those who were able to read and speak English. For the osteoporosis guide, we recruited women over the age of 50 years who were concerned about osteoporosis or had a history of osteoporosis. The sore throat guide was restricted to those who were currently seeking treatment for a sore throat. If the patient was a minor their parent could agree to participate in the study and be interviewed. For the heartburn guide, the patient must have been seeking treatment for heartburn, either as a new or pre-existing problem. Pregnant women were excluded from participating in the heartburn protocol.

Patient recruitment was conducted between July, 1999 and February, 2000. Each site was asked to recruit 10 patients per target condition. Physicians were also required to select 3 control patients who conformed to the selection criteria and who presented themselves in their office with the appropriate condition prior to the study period. The controls did not receive a guide in the course of their treatment.

Signs were placed in the reception areas and examination rooms of the physician offices and in the relevant over-the-counter (OTC) sections of the pharmacies, informing patients that a Health Canada-funded study was underway and that information sheets for specific conditions were available.

Patients who agreed to participate were asked to fill out a brief tear-off questionnaire/consent form located at the bottom of the guide. In British Columbia, and for some offices in the other two regions, patients were asked to sign a formal consent form along with the questionnaire. Patients were then telephoned by one of our interviewers 1 to 10 days after receiving the guide, and were asked a series of questions pertaining to the guide. In addition, the charts of those patients who received their guides in a physician's office, along with a selection of control patient charts, were reviewed in the physicians' offices.

A small sub-study of the osteoporosis guide was done with a sample of people who responded to a questionnaire after they reviewed the guide over the Internet. These respondents were volunteer seniors who were invited by Prevention Source BC to participate in the study.

Data Collection:

Data were collected through the following methods:

- **19 focus groups were held with physicians, pharmacists and patients in Nova Scotia, Ontario and British Columbia.**

- **Electronic questionnaires were received from 90 seniors across Canada** who accessed the osteoporosis guide on the project website or by email.

- **Tear off questionnaires were received from 1409 patients** across the three participating provinces who enrolled in the study in a physicians' office or a pharmacy. The patient's initial impressions on the helpfulness and clarity of the information were elicited, and our offices were provided with contact details to conduct the longer patient interview.

- **1176 patient telephone interviews were completed; (386 from pharmacies and 790 from physician's offices).** This structured telephone interview was conducted within ten days of the clinician visit, and was used to assess the patient's experience with the guide and subsequent treatment (Appendix E).

- **The charts of 859 guide patients and 412 control patients were audited** in the physicians' offices. This information was used to determine how the guide influenced patient care, including the choice of prescription or non-prescription therapies, whether treatment options were discussed and whether any relevant diagnostic tests were done. (Appendix F).

- **Exit interviews were conducted with 53 physicians and 30 pharmacists** (which included clinicians who, for whatever reason, withdrew from the study) for additional feedback on the conduct of the study as well as an assessment of their perceptions of the utility and value of the guides. These were primarily face-to-face interviews, but some were conducted via telephone or fax. (Appendix G).

Project Activities:
As noted above, the Canada Drug Guide Project involved three distinct phases, with various project tasks being allocated on a regional basis. The Centre for the Evaluation of Medicines in Hamilton, Ontario managed the overall evaluation and the focus group data collection; the literature review and guide development was led by the BC team; and the project evaluation was developed by the investigators in Nova Scotia.

Phase 1: Analysis of Literature

An environmental scan (Appendix H) and literature search (Appendix A) were completed. A comprehensive collection of the currently available patient-oriented drug guides on the three sentinel conditions was gathered and assessed.

Phase 2: Needs Assessment & Guide Development

This phase involved researching what patients wanted to know about medication treatment options, and developing and refining treatment guides based on these needs. The research team developed, designed, tested and printed two page illustrated guides in lay language to inform patients about therapeutic options in the treatment of sore throat, heartburn and osteoporosis. The guides were tested with 19 focus groups of consumers, physicians and pharmacists in BC, Nova Scotia and Ontario.

Phase 3: Evaluation of the Guides

An evaluation protocol was developed and submitted for ethical review (Appendix I). Ethical approval was received for the evaluation from the three participating universities before beginning this phase of the study.

Participants and Partners:
A project steering committee was established, forming a working committee of five investigators. The project investigators were:

- Mitchell Levine, MD and Lisa Dolovich, PharmD, Centre for the Evaluation of Medicines in Hamilton;
- Jean Gray, MD, Office of CME and Karen Mann, PhD, Division of Medical Education, Dalhousie University, Halifax; and,

- James McCormack, PharmD, Faculty of Pharmaceutical Sciences, UBC, Vancouver.

The project was administered by Alan Cassels through the BC Ministry of Health. Michelle Proctor-Simms in Nova Scotia, Sheri Burns in Hamilton and Lee Boshell and Anne Smith in Vancouver were hired as the individual regional coordinators, who oversaw the guide's implementation and evaluation. Kalpana Nair in Hamilton managed and facilitated the focus groups, and analyzed the results.

A federal-provincial advisory committee was established, with representation from Health Canada and from the provincial drug benefits programs in the three participating provinces (Nova Scotia, Ontario and British Columbia).

The project also fostered working relationships with other agencies involved in studying, producing or distributing patient-oriented therapeutic information. These organizations included:

- the Canadian Pharmacists Association;
- the Federal/Territorial/Provincial Working Group on Drug Utilization who funded the Consumer Education and Information Survey Project (Barbara Mintzes and Tom Walker);
- the Canadian Health Network;
- the Consumer's Association of Canada;
- the Centre for Health Information Quality, Oxford, England; and
- Prevention Source BC.

Deviations from the Original Proposal:

The initial literature search found that patient-oriented drug information which is mediated by a professional, and used to confirm and enhance verbal instructions from that professional, is more likely to have an impact on patient behaviour than information which the patient accesses in isolation. In response to the literature, our project departed from the original proposal (which was to test the impact using multiple dissemination methods) to concentrate more on understanding how an evidence-based guide can be used in the interaction between the patient and the health care professional.

When it became apparent that our library of existing patient drug guides did not contain any guides that met our specifications—that is, there were no existing guides that were evidence-based, had involved the consumer in production and were clearly written in language accessible to lay people-- we proceeded to develop our own. Despite the mountain of patient-oriented drug information available in the health care marketplace, there was a paucity of material that delivered evidence-based therapeutic information discussing the risks and benefits of even the most common therapies. We proceeded to create and test prototypes with focus groups of consumers, physicians and pharmacists. We took the best available evidence, and in consultation with the end-users, shaped the information so that the resulting guides would be brief but clear, comprehensive and useful.

PROJECT RESULTS, OUTCOMES AND IMPACTS

Results and Significant Findings:

The Canada Drug Guide demonstrated that an evidence-based information tool, such as a brief, one page (printed on both sides) therapeutic guide, could be used in clinical practice to provide patients with useful information and to help with therapeutic decision making.

Our focus group study revealed a high level of interest and an expressed need for patient-oriented drug information to assist patients in their therapeutic decision-making. There were very few regional differences in the desire of patients to be better informed about prescription drugs, or in their need to be involved in decisions affecting their health. Patients across Canada reported that they appreciate receiving additional written information on their conditions and the corresponding drug and non-drug methods of treatment.

The Canada Drug Guide evaluation phase of the project studied the benefits of providing patients with balanced information on a set of heterogeneous conditions. One of the most notable outcomes was the very high level of clinician and patient satisfaction with the quality of the information sheets across the various conditions. Overall, 84% of participating physicians and 85% of pharmacists found them "useful," and 98% of physicians and 92% of pharmacists reported that the guides "helped their patients understand the issues."

One of the original goals of the study was to disseminate and evaluate existing evidence-based consumer drug guides, yet the scan of existing patient drug information did not uncover material that met the minimal requirements of being evidence-based.

Key Messages

- **The Canada Drug Guide pilot study produced and evaluated drug information guides targeted at three separate conditions which physicians, pharmacists and consumers found useful and easy to understand.**
- **Between 80-90% of patients using the guides found them easy to understand; 48-60% of patients using the guides reported a moderate to very large influence on their decision making. Sore throat guide users reported their guide had the highest impact on treatment decisions.**
- **Focus Group participants (non-clinicians) wanted information about treatment options, as well as information of a drug's side effects, appropriateness, duration of therapy and costs. Clinicians raised concerns about the feasibility and impact such disclosure might have on patient care**.
- **Our most objective evaluation measure (chart audits) revealed that the use of the guide had a significant impact on the counseling that patients received in the treatment of sore throat and heartburn, especially with respect to diet and other non-drug measures to control and treat symptoms.**
- **Among active users of therapy for the prevention or treatment of osteoporosis, guide users were less likely to use a bisphosphonate and more likely to use hormone therapy than the control patients who did not receive a guide. (this data is not adjusted for potential confounders; inferences regarding the impact of the osteoporosis guide cannot be made until a comprehensive analysis is completed.)**
- **98% of physicians and 92% of pharmacists reported that the information guides helped their patients understand the issues involved in their treatment.**
- **53% of physicians thought the information would have an impact on drug use and selection.**

Project Results:

Fifty-three physicians and thirty pharmacists enrolled 1409 patients in this study to provide feedback on the guides. Patients and clinicians involved reported a very high level of satisfaction with receiving this patient-oriented material and a desire to see guides produced on other conditions.

The study process created some extra demands on office and pharmacy staff time, and thus may not realistically reflect the potential use of drug information guides with patients. Both physicians and pharmacists said that they would expect a higher utilization of the guides outside the confines of a research study. It is possible that the consent processes may have prevented some patients from participating. Staff support from in-house pharmacists, nurses and receptionists was essential in ensuring that the guides were given to the appropriate patients.

Physicians and pharmacists found that it was sometimes difficult to remember to use the information with their patients because of the time pressures of clinical practice, or lack of sufficient staff. Unlike Nova Scotia and Ontario, guide users in BC were required to fill out an additional consent form, which may have contributed to their reduced enrollments. In addition, many physicians and pharmacists, particularly in Hamilton, were involved in multiple studies at the same time as the Canada Drug Guide. This may have decreased the time and focus spent recruiting patients into the Canada Drug Guide study.

Transferability and Generalizability: The Canada Drug Guide involved physicians and pharmacists from urban, rural, solo, and multi-practice settings, and included fee-for-service and salaried clinicians. There were no differences in the clinicians' reports of usefulness and acceptability of the drug guides. As well, no differences were attributable to patient gender, location, or how the patients received the treatment guide (from physician or from pharmacist).

The uniformity of our results across the three jurisdictions, and in a broad range of practice settings, supports the conclusion that our findings are highly transferable to a wide variety of clinical settings. This suggests that the critical factor in determining the applicability of our results in any particular setting will be the degree to which the attending physician or s pharmacists is receptive to using information tools to involve patients in therapeutic decision making.

Applicability of Results

- **Results are relevant to a wide range of clinicians interested in using information tools with their patients.**
- **No difference in perception of the guide, or its impact, was noted between patient recruited in Vancouver, Hamilton or Halifax.**

Evaluation Results:

The findings of this study come from five separate evaluation vehicles including:

- *FOCUS GROUPS WITH CLINICIANS AND CONSUMERS*
- *INTERNET SURVEY OF SENIORS*
- *TELEPHONE QUESTIONNAIRE WITH GUIDE USERS*
- *CHART AUDIT OF GUIDE USERS AND CONTROLS*
- *EXIT INTERVIEWS OF PARTICIPATING CLINICIANS*

Focus Groups:

The focus group discussions revolved around three specific themes:

- the general medication information needs of patients;
- patient information needs for the three conditions portrayed in the guides; and
- clinician views of patient information needs.

Many patients reported wanting both written and verbal information, so that the printed information supported and reinforced the words of their doctor, and they could review the information later on their own time. Lack of trust in the information sources and biased messages were concerns raised by the participants in the focus group discussions.

The focus group findings revealed a disparity between the kind of drug and therapy information consumers say they want and what the physicians and pharmacists seemed willing to give them. While there was strong patient preference for information on treatment options, benefits and risks, including side effects of medications, some clinicians raised concerns about the feasibility and impact such disclosure might have on patient care.

We concluded that patients need meaningful, simple and complete information on their conditions, as well as a balanced sense of the risks and benefits of treatments. Understanding the information needs of patients will ultimately assist clinicians in providing meaningful and appropriate care for their patients.

The top five questions patients have when receiving a medication (in order of frequency mentioned in focus groups)

1) **How can this medication harm me? (side effects & risk information)**
2) **Is this the right treatment for me? (appropriateness of treatment)**
3) **How long do I have to take this medication? (duration)**
4) **What will it do? (indication of medication)**
5) **What will it cost? (cost to patient of medication.)**

Internet Survey of Seniors:

Data on the usefulness of the osteoporosis guide were collected from a unique sample of seniors across the country who were comfortable using the Internet to access the questionnaire. While this sample probably represents a fraction of the senior population, there was a high level of satisfaction with the osteoporosis guide among this study sample. (See Appendix J)

This survey used a convenience sample of 90 seniors who belonged to several national seniors' organizations. Questionnaires were collected via e-mail and analyzed.

Nearly half (42%) of the participants reported that they already practiced many of the preventive measures mentioned in the guide. Another 14% expressed an intention to adopt new lifestyle practices as a result of the guide, and 9% reported adopting a new lifestyle practice as a result of reading the guide.

Further research will need to be conducted to assess the representativeness of this sample in terms of the overall Canadian senior population. In addition, the use of the Internet to deliver this type of therapeutic information will need to be evaluated to measure the impacts of medication awareness among seniors.

The Canada Drug Guide tool is feasible for Internet delivery. As access to therapeutic information via the Internet increases a tool such as the Canada Drug Guide could be used to disseminate therapeutic information to a wider audience.

Characteristics of the senior population completing Internet survey:

- **85% access e-mail and the internet on a frequent basis;**
- **69% preferred to access the information via the Canada Drug Guide web site, as opposed to having it emailed to them.**
- **83% expressed a wish to have access to other Canada Drug Guides in the future.**
- **The internet proved to be a quick and easy method of obtaining feedback from a relatively small volunteer sample**

Telephone Questionnaire Results:

The main evaluation tool used to assess the impact of the Canada Drug Guides on patients was the telephone interview. These interviews, which lasted approximately 15 minutes, contained 27 questions on the patients' experience with using the guides. 81% (1176) of patients were interviewed within 10 days of receiving the guide in a clinical setting (physician's office or pharmacy). The following analysis is based on the results of these 1176 interviews.

Patient demographics:

Approximately 80% of patients contacted were women.

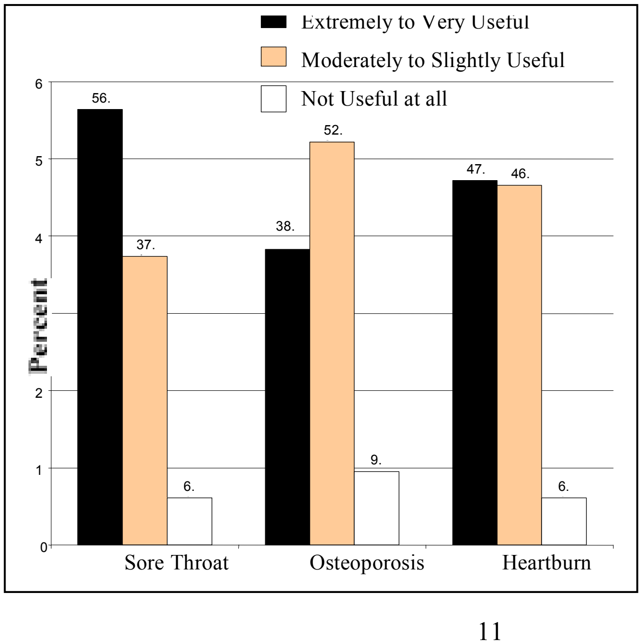
Older patients were more likely to be provided guides pertaining to the chronic conditions (heartburn and osteoporosis), and younger patients, the acute condition guide (sore throat) For example, 90% of sore throat guide users were under 60 years old. The average age for the osteoporosis guide users was 60.

The overall average age for all participants in the study was 50 and there were no significant differences in regard to patient gender or average age across the three provinces.

Usefulness of the Guides

Patients were asked to rate the usefulness of the guide. About half of the participants rated the guides at least "very useful" or higher. Specifically, 56 % of sore throat, 47% of heartburn and 38% of osteoporosis patients rated the guide as "Very" or "Extremely" useful. Only 9% of patients stated the information was "Not useful at all" (Figure 1).

Figure 1: Usefulness of Guide by Condition



How the Guide was used by patients

The guides were used in a variety of ways. 38-40% of patients stated that the guide was used in discussion with the physician/ pharmacist, or the clinic pharmacist/ nurse.

Helpfulness of the Guide:

Of the respondents, 58% (osteoporosis), 67% (heartburn) and 72% (sore throat) reported that the information helped them make decisions about their treatment.

When asked how the guide was helpful, more than half (51-59%) of patients reported that the information guide gave them "treatment options and helped them make a treatment decision." Respondents also reported that the guide gave them a "greater knowledge or understanding about their condition," (reported by 25% of the respondents). Of the 404 (34%) patients who reported that the information sheet did not help them, 86% to 93% indicated this was because they were already familiar with the information.

The sore throat guide was more likely to be reported as "helping understand the clinician's reasoning" (23%), whereas the osteoporosis and heartburn guide were more likely to be helpful in providing greater knowledge of the condition (19%).

Influence of the Guide

When asked as to the "degree the information influenced your [the patients'] decision about taking medication or treatment," approximately 30% to 40% reported "no influence," with 60% of sore throat, 55% of osteoporosis and 48% of heartburn patients reported a "moderate" to "very large" influence on their decision. The sore throat information had a higher degree of influence on the treatment decision taken by the patient than the other two guides.

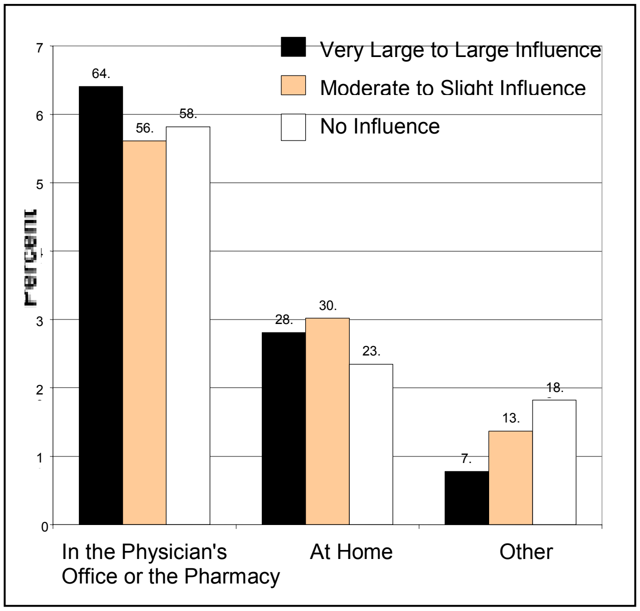
However, regardless of the self-reported degree of influence the guide had, most patients felt that they made their decision about treatment with their physician (49-61%), and about a third reported making their decision at home (24- 30%) (Figure 3).

The influence of the guides by condition was fairly consistent with the sore throat guide showing the highest degree of influence on patient decision making. (See Table 1)

Table 1: Degree of Influence of the Guides

	Sore Throat	**Osteoporosis**	**Heartburn**
Very Large to Large Influence	34%	29%	21%
Moderate to Slight Influence	36%	34%	41%
No Influence	30%	37%	38%

Figure 2: Influence of Guides against where the patients made their treatment decision



Main Messages of the Guide

Patients were asked to describe what they felt was the main message of the guide that they had received. The answers to the "main message" question clustered around knowledge of treatment options or a general understanding of their condition. We noted that for osteoporosis and heartburn guide users, 11% of respondents reported that prevention information or knowledge about the causes of their condition was the main message for them. The sore throat guide users did not mention prevention.

Telephone Questionnaires:
Main findings

- **Two-thirds to three-fourths of patients took the information guide home to read first, while the rest reviewed the guide with their physician or pharmacist**
- **The information guide for sore throat generated a higher rating of usefulness and influence on decision making than the other guides**
- **80-90% reported that the guides were "Very Easy" to understand**
- **60% of sore throat; 55% of osteoporosis and 48% of heartburn patients reported a "Moderate" to "Very Large" influence of the guide on their treatment decision**
- **73% of the total guide users said that the main message they took away from using the information guide was either "treatment options", "general information" or "a greater understanding of their condition".**

Chart Audits:

The chart data were analyzed to determine how receipt of the guide by a patient affected the patient's subsequent treatment, both in terms of the prescriptions written and the counseling or other non-drug measures used. The forms used to guide the auditing of charts can be found in appendix F.

One would expect the differences from the one-time use of an information guide to be small. We have found that there were three areas of statistically different results (above the 95% confidence interval) between the guide users and control patients. (See box)

Altogether 859 patients had their charts audited and 412 patients acted as controls. The demographics of the participants in the chart audit portion of the study are outlined in Tables 4,5, and 6.

Chart Audit: Main Findings

- **Sore Throat: A 39% decrease [Odds ratio=0.61, 95% CI=(0.98,0.38)] was noted in the charting of treatments 'other' than antibiotics, non-drug treatments such as gargling with salt water or cough syrups/ lozenges for patients who used the guides. Patients who received the guide were less likely than the control patients to have other treatments such as OTC medicines, inhalers, mouthwashes and other symptomatic treatments, noted in their medical charts.**
- **Heartburn: A 77% increase [odds ratio=1.77, 95% CI=(0.99,3.19)] was noted in the charting of 'non-drug' measures among the heartburn guide users. As our guide spent a good portion of the space devoted to informing the consumer of the lifestyle, diet and other non-drug measures to control the symptoms of heartburn, it might be expected that the physicians treating patients with the guide would note in their charts that these non-drug measures were counseled to the patient.**
- **Osteoporosis: Amongst active users of therapy for the prevention or treatment of osteoporosis, patients receiving a guide were less likely to use a bisphosphonate (odds ratio= 0.34, 95% CI 0.54, 0.21) and more likely to use a hormone therapy than the patients who did not receive a guide (Odds ratio= 1.42, 95%CI 0.94, 2.15). Unless these data are adjusted for baseline conditions and other potential confounders it is not possible to consider any causal association between the guides and treatment use. Any inferences regarding the latter should be withheld until a comprehensive analysis is completed.**

Table 2 Chart Audit demographics—Sore Throat

Sore Throat	**Total #'s**	**% Female**	**Mean age**	**% ≤ 60**	**%BC**	**%ON**	**%NS**
Control	**137**	**70.1**	**30.4**	**91.2**	**18.2**	**36.5**	**45.3**
Guide	**296**	**76.4**	**30.6**	**93.9**	**12.8**	**35.1**	**52.0**

Table 3: Chart Audit demographics—Reflux

Reflux	**Total #'s**	**% Female**	**Mean age**	**% ≤ 60**	**%BC**	**%ON**	**%NS**
Control	**137**	**74.5**	**50.1**	**72.1**	**21.2**	**32.8**	**46.0**
Guide	**279**	**64.5**	**50.8**	**70.5**	**20.4**	**27.1**	**52.5**

Table 4: Chart Audit demographics—Osteoporosis

Osteo	**Total #'s**	**% Female**	**Mean age**	**% ≤ 60**	**%BC**	**%ON**	**%NS**
Control	**138**	**99.3**	**65.0**	**38.7**	**18.8**	**34.1**	**47.1**
Guide	**284**	**100**	**59.4**	**59.9**	**20.8**	**23.6**	**55.6**

Exit Interviews:

At the end of the study we interviewed the 53 physicians and 30 pharmacists who were involved in enrolling patients. Most of these interviews were done face-to-face, though a few were completed by fax or over the telephone.

Main findings: physician and pharmacist exit interviews

- **98% of physicians and 92% of pharmacists reported that the information guides helped their patients understand the issues involved in their treatment.**
- **84% of physicians and 85% of pharmacists them found them useful.**
- **97% of physicians and 86% of pharmacists thought that the level of reading material was generally appropriate for their patients who received the guide. (the other 14% of pharmacists said it was too simple; none said it was too complex)**
- **19% of pharmacists said that their management of patients (information counseling) to whom they gave the guide differed from their usual management of patients.**
- **53% of physicians thought the information would have an impact on their drug use and selection.**

PRACTICAL IMPLICATIONS FOR PROGRAM AND SERVICE DEVELOPMENT

The Canada Drug Guide pilot study amassed a wealth of experience in researching, creating, field-testing and evaluating drug information for consumers. Above all, this experience demonstrated that developing quality therapeutic information and accurately assessing its impact is a challenging task.

To develop useable, pertinent and high quality information tools, one has to balance the most up-to-date evidence of therapeutics with the stated needs of patients. The information also has to be focussed, simple, concise and engaging. While creating information tools that meet these criteria is difficult, the feedback from clinicians and patients indicated that the guides used in the study were successful, i.e. the users appreciated and used them.

In developing these three prototype guides we focussed on identifying the appropriate concepts, vocabulary, design and breadth of information to include in the guides. Future work should include developing guides in different languages, at different reading levels, and on different topics.

The most important practical implication drawn from the focus group data, the telephone interviews and the chart audits was that patients and clinicians need more opportunities to obtain objective, relevant, and individualized patient information. The material needs to be in a format that enables patients to absorb and understand the information easily, but which doesn't require too much additional time of the clinician to explain. It is important to note that both clinicians and patients saw verbal and written methods of disseminating information, when used in combination, as most successful in reinforcing the health messages being given.

While this project did not study patient satisfaction, or improved knowledge levels, or if medication compliance/adherence was improved there is clearly a need for future study of these issues.

Information tools should be:

1. **Simple, easy to understand, based on evidence, and reflect the expressed needs of patients.**
2. **Easy to store, retrieve and transport**
3. **Created to be integrated into many different points of office and pharmacy processes so that there are more opportunities for discussion.**
4. **Self-accessible, so that consumers are able to use them, yet able to be tailored by a health professional to a patient's specific set of needs**
5. **Accessible in different formats, languages and media to reach as wide an audience as possible.**

Policy Implications and Recommendations:

This study has indicated a need to continue to carry out policy-relevant research in the area of consumer drug information. While it is important that consumers have access to patient-oriented, evidence-based drug information of a high quality, this information should undergo continuous and rigorous evaluation to assess its impact. Well-developed therapeutic information can have a great impact on therapeutic decision making and medication use by patients and clinicians.

Consumers are subject to great quantities of drug marketing information so there is a need for independent drug information of high quality. Drug and health information currently available is often irrelevant, outdated or presents the bias of those who produce it, instead of reflecting the needs of consumers.

Patients need tools to help them assess the whole range of drug and non-drug treatments, specifically the risks and benefits of drug therapies

Consumers have reported that they would benefit from one credible, trustworthy source, which can be used at the time when they most need it—during a visit to a health professional such as a physician or pharmacist. The focus groups revealed that condition-centric, not drug-specific information is what most people want first so that they can understand their therapeutic choices within the context of their illness. Then, if it is determined that a drug is the most appropriate treatment for a particular condition, the patient would benefit from being provided with high quality, product-specific information guides.

Policy implications that apply to creators and disseminators of drug information:

- **Patients and clinicians want access to an evidence-based and user-friendly drug information tool that is easily updated**
- **Patients will better understand drug information if it is provided in a meaningful context including reliable, easy-to-understand information about their disease or condition.**
- **Drug information research must involve the users of the information and be integrated into the present realities of the doctor-patient-pharmacist interaction.**
- **More research into the impacts of objective drug information on health outcomes has to be done.**

Ideally, projects that disseminate and assess information tools over the long term will provide more meaningful data on the impact of that information. Thus, longer-term research around disseminating and evaluating drug information tools should be encouraged.

Potential Impacts to the Reform of Canada's Health Protection Legislation:

There are several potential impacts that this study may have on the proposed reforms of Canada's health protection legislation.

First, although Health Canada currently oversees programs that regulate therapeutic products (Health Protection Branch) and health promotion and disease prevention programs (Health Promotion and Programs Branch), there is a potential central role for Health Canada to coordinate the provision of credible, evidence-based drug information for Canadian consumers. Consumers would benefit from having access to a central and trustworthy source, such as a compendium of therapeutic information sheets modeled on the "Canada Drug Guide" prototypes evaluated in this study.

All treatment guides must be able to assist patients to participate in discussions with their physician about their treatment options.
Education for consumers should not centre on specific drugs, but should include explanations of disease etiologies, self-care information, drug and non-drug treatment options, treatment risks and benefits and comparative costs of treatments. Health related websites such as the Canadian Health Network are possible venues for disseminating this information.

Second, based on the results of this study, therapeutic information must reflect the best available evidence of effectiveness, be accessible, comprehensible and useable, and involve patients in its development. The provision of patient drug monographs, which would disseminate product specific information to patients, must enshrine the principles of quality drug information in order to be truly effective.

Third, the outcomes of ongoing discussions around "direct-to-consumer advertising" (DTCA) of pharmaceuticals will have a profound effect on the quality of drug information to which consumers will be exposed.

The future of independent drug information in Canada is intertwined with the laws governing DTCA. Legislation loosening the commercial ban on drug advertising and allowing increased direct marketing prescription drugs, and advertising targeted at specific illnesses or conditions, will leave consumers even more vulnerable to the adverse effects of bias than they already are. Commercial sources of drug information, including the pharmaceutical industry, have a range of strategies for influencing drug use, including advertising, public relations, lobbying, enticements to health professionals, and drug journals. These sources are very well designed to promote and maximize, not rationalize, the use of prescription drugs. Our findings indicate that clinicians are feeling the pressures of the demands of patients who access drug information from the Internet or from commercial sources. Physicians report that they often take time to disabuse patients of drug notions picked up from commercial sources. Further advertising of prescription drugs is likely to exacerbate this imbalance, as it does not provide the balanced information people say they need to participate meaningfully in their health decision making.

Good Quality Drug Information is:

- **Based on the best available evidence of effectiveness.**
- **Accessible, comprehensible and useable.**
- **Involves patients in its development.**

(based on NHS Centres for Reviews and Dissemination)

DISSEMINATION PLAN

Beginning in October 1999, the Canada Drug Guide Project has conducted an ongoing program to disseminate the results of the project (Appendix K). After the final report is delivered to Health Canada in August, 2000, the research team intends to use the remaining year to disseminate the project findings to academic audiences, decision makers (including administrators and managers of national and provincial drug benefits programs) and the general public. All of our findings will be published and accessible on our website:
www.canadadrugguide.org

Decision-makers:

The research team will target decision-makers, including those who operate on various levels and in various capacities connected to patient drug information. One of the key decision-making bodies is the Federal/Provincial/Territorial Working Group on Drug Utilization. The Working Group reports to the Pharmaceutical Issues Committee (PIC), which in turn reports to the Deputy Ministers of Health. PIC is the main intergovernmental forum for the discussion of pharmaceutical issues in Canada. As utilization of pharmaceuticals is a key concern for PIC, we will ensure that they will have full access to the results of the research.

The consultative activities being planned around Health Canada's "Legislative Renewal" process will also provide important venues for the research findings. The results of our systematic examination of patient concerns around drug information will be particularly useful to this process.

The research team intends to be involved in consultations concerning:

(i) the planned changes to legislation affecting
(ii) direct to consumer advertising **(DTCA);** and
(ii) planned revisions on the **'Information to Patient Template'** of the product monograph (PM), carried out by the Therapeutic Products Program at Health Canada.

It is anticipated that these consultations, taking place over the next year, will benefit from a thorough understanding of the drug information needs of Canadians examined by our project.

The participating provincial drug benefits managers in Ontario, BC and Nova Scotia as well as other Canadian provinces, will also be a primary target audience. Presentations on our project with the BC Ministry of Health and Ministry Responsible for Seniors have already been conducted. These managers will receive the final report, and study investigators will be available to brief them on any policy recommendations emerging from this research.

Academic Audiences

We will attempt to publish our findings in a variety of academic publications; specifically those interested in reporting on the acceptability, utility and impact of independent patient information on physicians, pharmacists and patients. Examples of these publications include major medical journals such as the CMAJ (Canadian Medical Association Journal); JAMA (Journal of the American Medical Association); or the BMJ (British Medical Journal). As well, specialized publications such as Health Expectations that report on the involvement of patients and their advocates in decisions about individual healthcare will be included.

The target audience of the publications will primarily consist of physicians and medical academics. An example of our academic outreach so far is the report of the focus group consultations with patients, physicians and pharmacists which we presented as part of a poster presentation to the annual American Society of Clinical Pharmacology and Therapeutics conference in April, 2000. This presentation described how the focus groups were used to develop the treatment guides, and to systematically research patients' treatment information needs (Appendix L).

Public Audiences

The research team also intends to disseminate the research findings through participating in discussion groups, workshops and conferences directed at the public, some of which we have already completed. One example in this area was a presentation to the HAI (Health Action International) Europe group in Amsterdam in November, 1999 and an article in their quarterly newsletter "HAI-Lights" (to be published in the fall, 2000) describing our findings. As we publish more academic articles we intend to arrange investigator interviews with the popular press, particularly newspaper and magazine writers interested in patient access to health information.

Other than several newspaper articles appearing in August, 1998 announcing the launch of the Canada Drug Guide Project and other HTF projects, our research has not had any media exposure.

APPENDICES

A. Literature Review
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D. Description of Focus Group Design: Patient and Clinician Perception of Patient Medication Information Needs
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K. List of Presentations, Posters and Papers
L. Poster Abstract to the American Society for Clinical Pharmacology and Therapeutics Conference, Los Angeles, March, 2000
M. Bibliography

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Appendix A:
Literature Review of Patient Drug Information
Canada Drug Guide Project

In its 1997 background report on Pharmaceutical Policy in Canada, the National Forum on Health found that "governments are not doing enough to inform consumers, provide access to essential pharmaceuticals, control prescription and non-prescription drug expenditures, and encourage research on new chemical products."[1] Part of Health Canada's response to this report was the creation of the Health Transition Fund, a 150$ million, two-year program set up to fund pilot and demonstration projects in areas where our health system was making transitions to new models of care. Funding was provided to a proposal entitled the Canada Drug Guide Project, a pilot study to create and evaluate the use of an objective, authoritative, national drug information guide that is easily accessible to consumers when they need it.

One of the major health transitions in our medical system is towards greater patient involvement in decision making and self-care. "Information Therapy" is a new term that refers to the process of enabling patients to improve their ability to make informed decisions concerning their own health care by supplying them with information. [2]

The best assessment of the available literature on patient drug information and education in Canada can be found in a 1998 "Survey of Patient Information and Consumer Education on Prescription Medicines" commissioned by the Consumer Education and Information Project of Canada's Federal/Provincial/Territorial Utilization Task Force[3]. The authors of this study conclude that:

> most large projects were either carried out by the pharmaceutical industry or funded by the industry, often with industry involvement in project planning. The impact of this strong commercial presence on the types of services or information provided is unknown. However, the need for independent information on drugs, both for prescribers and the public, has been identified by the World Health Organization as a precondition for successful national drug policy and promotion of more rational drug use[4]

Much of the literature on patient drug or health information suggests a strong correlation between an informed, knowledgeable patient and the patient's subsequent health outcome.[5] Consumer education may provide a vehicle for reducing inappropriate prescribing or noncompliance through patient involvement in decisions about taking medications. Much of what is referred to as "noncompliance" is due to inadequate communication about drugs. As many as 30-55 % of patients deviate from their medical regimens. [6] More communication around pharmaceuticals, whether in verbal or written form, can have direct health impacts. Studies report that between 5 and 23 percent of hospitalizations are associated with inappropriate use or non-use of prescribed prescription medications. [7],[8] While health professionals can see a direct link between better informed patients and their health improvement, patients are becoming increasingly vocal on the need for more information about both drug and non-drug therapies. Most sources of information are not well-designed to help people make informed decisions. Much of the educational material presently available on conditions typically treated with pharmaceuticals are produced by the drug industry.[9]

The numbers of drugs is increasing and direct-to-consumer advertising in American media pervades Canada. This leads to a situation where much misinformation exists [10] and few agencies seem willing to produce the kind of evidence-based, unbiased, comprehensive, patient-oriented materials that are essential to properly inform patients. Much of the literature on patient education emphasizes that written educational pamphlets can contribute in an important way to patient involvement in the treatment of their condition if it is delivered at a 'teachable moment'. Passive information, which is not contextualized by a health professional has been shown to be less effective.[11] Receiving a fact sheet alone had no significant effect, whereas having discussed it with a health care professional was associated with a significant increase in knowledge about medication. [12] If patients are to be active participants in decisions about their care the information they are given must accord with available evidence and be presented in a form that is acceptable and useful. There seems to be uniform consensus around the ideal qualities needed for patient-oriented information. Information that helps people participate in an informed way in decisions about their health care should:

1. provide relevant information about different options and their outcomes.
2. reflect the best available research evidence of health care effectiveness, and,
3. be presented in a way that is accessible, comprehensive and usable to its intended audience. [13]

Providing evidence-based information to the general public is a difficult enterprise especially given the predominant myths surrounding the effectiveness of medicine and the paternalism latent in the doctor-patient relationship [14] There is thus a great need for a balanced, evidence-based approach in the production in patient-oriented materials.

The Kings Fund in London has done rigourous study of the use of evidence and research based information for consumers. As a way of summarizing their research, they maintain that: "if information materials are to be used to support patients' involvement in treatment decisions, they must contain relevant, research based data in a form that is acceptable and useful to patients"[15]

Overly optimistic or inaccurate statements could supply a false impression of a treatment's likely benefits. A major fault is emphasizing the benefits and ignoring or glossing over risks and side effects[16] Studies of doctor-patient communication about medication overwhelmingly report that the discussion of benefits and risks, as well as discussing a patients' opinions around the prescribed medications will improve the patients' ability to follow through on their treatment plan. [17] As Angela Coulter points out: "An overly optimistic view of medical treatments could foster demand for inappropriate interventions, leading to iatrogenic harm, increased dissatisfaction, and unnecessary costs."[18]

Caregivers are starting to understand the importance of providing information to support patients' participation in choosing treatments and deciding on strategies for managing their health problem [19] But this information must be complete. The “prescription” ought to include not only the drug and dose, but information about treatment, practical suggestions, proposed schedules, warnings about what side effects to watch for, and referrals for additional help, such as counselling. [20] As Coulter and Richards point out: “current information materials for patients omit relevant data, fail to give a balanced view of the effectiveness of different treatments, and ignore uncertainties “[21]

The format of the information that the patient receives is very important factor, and very few information pamphlets available will report relative and absolute risk of medications. Patients’ views of medical therapy are shaped by the formats in which potential benefits are presented. Presenting absolute versus relative risk reductions significantly affect the kinds of treatment options a patient makes.[22]

As well, there is a lack of information about the optimal format and mechanism of transfer regarding medication information that patients want, or indeed need, to help improve their participation in the medication taking decision process. Coulter and Richards point out that “groups producing information materials must start with needs defined by patients, give treatment information based on rigorous systematic reviews, and involve multidisciplinary teams (including patients) in developing and testing the materials[23]

The availability of evidence-based patient information to inform choice is still limited. Patients criticise some materials for being superficial, patronising and lacking detail, particularly about risks and alternatives.[24]

The Toronto Consensus statement on doctor-patient communication pointed out that in general, patient satisfaction with their care is closely tied to having received sufficient information, explanation and feedback from their doctors.[25] The two main sources of drug information for the patient is the physician or pharmacist.
Patients typically report that they want to get information from their physicians, often desiring much more information than the doctor is prepared to give. Doctors underestimate the information-seeking behaviour of most of their patients.[26]

A number of studies have shown that physicians and pharmacists who counsel patients about their prescription medications achieve better patient compliance and improved therapeutic outcomes. [27] Indeed, clinicians who counsel their patients on medication use often refer to leaflets, printouts, or other technologies to enhance their verbal instructions

Daphne Fresle and Cathy Wolfheim who conducted one of the world's most exhaustive surveys on patient education in rational drug use (Public Education in Rational Drug Use: A Global Survey, published by the WHO Action Programme on Essential Drugs) concluded in their 1997 study of drug education projects in over 38 countries that "

> There is a well evidenced and compelling need for
> public education in the appropriate use of drugs,
> with potential benefits to the individual, the community
> and policy-makers" (Fresle, Wolfheim, p. vi)

While the need for such education is great, the obstacles for achieving good evaluations of the impacts of this education are greater still. From their review they reminded us of the necessity of taking the 'long view' when measuring public education activities. They concluded that:

> "Much greater understanding is needed by supporting agencies that the impact of public education strategies may be incremental and move along a continuum of awareness raising, knowledge creation, community empowerment and behavioural change. This may be difficult to evaluate in the short-term particularly using classical methodologies" (Fresle, Wolfheim, p. vii)

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Participants Representing Patients: Focus Group Questions
Canada Drug Guide

A. GENERAL INFORMATION NEEDS ABOUT MEDICATION FOR MEDICAL CONDITIONS:

1. If you have (or have had) a medical condition, what do you want to know about the medication options?

   Prompts: types of medication, prescription vs non-prescription

   What information about medication options is most important out of all the things that we have talked about?

2. Where do you currently get information about medications when you have medical condition or concern?

   Prompts: From Where? From Whom? Format? (e.g. written vs verbal)

Is this meeting your needs? If not, why not?

3. Can any of you describe a situation where you wanted information about a medication but could not get it?

4. Can you describe a situation where you wanted information about a medication and were happy with what you received?

B. INFORMATION NEEDS SPECIFIC TO 2 CONDITIONS:

a) If you had osteoporosis:

1. What information would you want to know about osteoporosis? About treating osteoporosis?

2. How would you like to get this information?

   Prompt: From Where? From Whom?

b) If you had a sore throat:

1. What information would you want to know about sore throats? About treating sore throats?

2. How would you like to get this information?

   Prompt: From Where? From Whom?

ID#: _________ Date: ___________________

c) If you had GERD (heart burn):

1. What information would you want to know about GERD? About treating GERD?

2. How would you like to get this information?

Prompt: From Where? From Whom?

C. FEEDBACK ABOUT INFORMATION SHEETS

Hand out first information sheet and give participants a few minutes to look them over.

1. A) First, I would like you to think about the **Osteoporosis sheet** in a very general way.

What thoughts do you have about the:

÷Layout

÷Readability: Are there words that are hard to understand?

B) What parts of the sheet are not clear?

C) What changes would you make to this sheet (i.e. what would you add and what would you delete?)

2. A) Now, I would like you to think about the **Sore Throat sheet** in a very general way.

What thoughts do you have about the:

÷Layout

÷Readability: Are there words that are hard to understand?

B) What parts of the sheet are not clear?

C) What changes would you make to this sheet (i.e. what would you add and what would you delete?)

ID#: _________ Date: ___________________

3. A) Finally, I would like you to think about the **GERD sheet** in a very general way.

What thoughts do you have about the:

÷Layout

÷Readability: Are there words that are hard to understand?

B) What parts of the sheet are not clear?

C) What changes would you make to this sheet (i.e. what would you add and what would you delete?)

4. Would it be helpful if this information was made available to you at your physician's office? At your pharmacy?

5. If this information was put with other similar information sheets, would this be a useful for you? Why or Why not? Where would it be most useful to get these sheets?

6. If you could receive your own personal copy of this information (i.e. fax-on-demand) would this be helpful? Fax-on-demand means that there is a fax machine in the physician's office where you can fax a request for an information sheet and one would be faxed back to you.

7. When you read the information on these sheets, what piece of information is the most important to you?

8. What piece of information stands out for you the most when you read each of the sheets?

Appendix C:
Copies of Canada Drug Guides

[Not Available Electronically]

Osteoporosis

Sore Throat

Heartburn

Appendix D:

Focus Group Results
Patient and Clinician Perception of Patient Medication Information Needs

Background

One of the major health care transitions is towards greater patient involvement in decision making and self-care. Accordingly, patients increasingly need and want more information about their medications and nondrug therapies. However, much misinformation about medications exists. As well, few printed information sheets have included patients in their design and creation and most sources of information are not well designed to be decision guides. Patients in Canada are also subjected to the U.S. media's direct-to-consumer advertising and are needing to contend with the increasing number of drugs available. Therefore, there is a need for objective drug information that is easily accessible to patients when they need it.

Studies suggest that between 5 and 23 percent of hospitalizations are associated with inappropriate use or non-use of prescription medications. Some of this may be due to inadequate communication about drugs, resulting in 30-55 percent of patients deviating from their medical regimens. Consumer education may provide a vehicle for reducing inappropriate prescribing or noncompliance through patient’s increased involvement in decisions about taking medications. Therefore, the >prescription= for a drug ought to include not only the drug and dose, but information about treatment, practical suggestions, proposed schedules, warnings about side effects, and referrals for additional help.

Patients receive drug information from various sources including their physician, their pharmacist, drug company leaflets, lay textbooks, or electronically through the Internet. These varying sources of information tend to be incomplete or conflicting. There is also a lack of information about the optimal format and mechanism of transfer regarding medication information that patients want, or indeed need, to help improve their participation in the medication-taking decision process. Therefore, this study sought to assess the treatment needs, desires and expectations of patients to assist with the development of treatment information that facilitates patient involvement in therapeutic decision making.

Research Objectives

The present research was the first phase of a larger project whose main goal was to develop, disseminate, and evaluate evidence-based patient medication information. This initial phase took the form of a qualitative study and sought to answer the following questions:

1. What do patients want to know about the medications they are taking?
2. Do patients' information needs differ depending on the medical condition they are seeking information about?
3. Who do patients receive information from AND want to receive information from?
4. Do patients and clinicians share the same ideas about the types of information patients want to know about medications?

Method

Design:

This study used a qualitative design. Focus groups were conducted with patients to ask them about their medication-related information needs and to receive feedback on three evidence-based treatment information sheets (focused on sore throat, gastrointestinal reflux disease, and osteoporosis). Questions in the focus groups were primarily open-ended to allow participants to share their thoughts and feelings. A grounded theory approach was used to develop themes. After the data from the patient focus groups had been compiled, this was shared with physicians and pharmacists who answered open and closed-ended questions to determine their comfort with patients= ideas and the feasibility of implementing these ideas.

Participants/Subjects:

Participants for this project were sought from a number of sources. Patients for the initial focus groups were sought through the placement of advertisements and posters placed in a variety of locations. As well, the investigators contacted local agencies or companies to solicit their participation as a potential site for participant recruitment in order to improve the diversity of participants in this study. Participants fitting the following target criteria were recruited:

1) Age: over 65 years, between 25 and 65 years, and under 25 years,
2) Health Status: sick vs well, and
3) Socioeconomic Status (SES): low SES, middle SES, and high SES.

Physicians and pharmacists for focus groups in the latter part of the study were sought through personal contacts of the local principal investigators. Sampling for all focus groups was both purposeful and convenience. Patients received a $25.00 gift certificate to a grocery or retail store and physicians and pharmacists received a $100.00 honorarium for participation in the focus group. Parking expenses were also paid for all participants.

Inclusion Criteria:

Patients who were over the age of 18 years were eligible to participate if they were currently taking or had taken at least one medication.
Pharmacists and physicians who had practiced for at least 1 year in their respective profession in a clinical capacity were eligible to participate in the study.

Exclusion Criteria:

Patients were excluded from the study if they are deemed by their physician or the research assistant to have mental, cognitive, or linguistic difficulties.

Setting:

Focus groups were conducted in the communities of Hamilton, Ontario, Halifax, Nova Scotia, and Vancouver, British Columbia. All groups were held in locations that were easily accessible by public transportation. Refreshments were served in all groups.

Sample Size:

Sample size was estimated in consultation with a qualitative research expert and based on previous experience. Focus groups stopped (data stopped being collected) when theoretical saturation was reached. Eleven focus groups with patients and eight focus groups with physicians and pharmacists were conducted, for a total of 19 focus groups. Approximately, one third of each of the focus groups took place in each of the three test areas. Each focus group had between 3 and 12 participants.

Data Collection:

Focus groups were conducted using an interview guide consisting of 17 of open-ended questions that related to patient medication information needs and their feedback on the developed information sheets. The focus group guide was pilot tested to ensure clarity in the order, timing, and wording of questions. All groups were audiotaped. At least 2 members of the research team were present for each group, with one member facilitating the group and the other member taking detailed notes in case of tape failure. At the end of each group, the researchers completed a debriefing that included their perceptions of the group and what they felt had worked or not worked. All tapes were transcribed and cleaned. Based on feedback from earlier groups, the information sheets were continually revised and all participants were sent the final sheets.

Data Analysis:

Verbatim statements from the audiotapes and field notes were coded to identify common themes within and across patient and clinician subgroups. Each transcript was coded independently by at least two members of the research team using an operational codebook. The codebook was developed based on the research questions, from previous work in this area (Patient Views on Medication Study), and from material received from the first 2-3 interviews. The codebook was modified throughout the study based on any new data obtained. A qualitative data retrieval computer program, QSR NUD*IST (version 4.0) was used to assist with the organization of the data.

The themes generated were continually developed and explored during the data analyses stage of the study. This iterative analysis strategy meant that further analyses was conducted as new themes emerged. Summaries of each theme (code) were then completed by at least 2 members of the research team. The transcripts and summaries were reviewed to elicit both confirming and disconfirming data for the themes being generated. Following completion of theme summaries, 3 researchers discussed the findings to ensure that there was consensus for the reported findings.

Time Frame and Summary of Research Activities

Recruitment for focus group participants took between 1-2 months. Four months was needed to complete the focus groups and 3 months to analyze the data.

Ethics:

All potential participants were verbally informed during their initial contact with the research coordinator or research assistant that their participation was voluntary and that they were free to withdraw from the study at any point. All information was kept confidential by removing personal identifiers from all transcripts and not using any identifiers in reports or publications. All study materials were kept in a locked cabinet and access was restricted to those directly involved with the study.

Results

Table 1 below describes the final makeup of the focus groups. As noted in Table 1, there were 11 patient groups that were distributed proportionately across all 3 study sites. Groups were chosen to reflect the particular population of the study site. In Ontario, the five groups held included 1 group with ethnic patients (Italian), 2 groups of seniors, 1 group with patients that had a chronic condition and 1 group with those of low economic status. In Nova Scotia, the three groups held included, 1 rural group, 1 group with those of low economic status, and 1 group of those with a chronic condition. In British Columbia (BC), the three groups included, 1 rural group, 1 group with ethnic patients (Chinese) and 1 group of those with a chronic condition. In both BC and Nova Scotia the chronic condition groups were mainly seniors.

Table1: Number and Type of Patient Focus Group

Type of Patient Group (11 groups in total)						
	Rural	Ethnic	Seniors	Young Profess.	Low Income	Chronic Med. Cond.
ONT		1 (Italian)	2	1	1	1
NS	1				1	1
BC	1	1 (Asian)	1			
Comments	Mix of age, SES, and HS		Mix of SES & HS	Mix of HS	Mix of HS & age	Mix of SES & HS

OTHER: Physician and Pharmacist Sampling: 2 of each group in ON; 1 of each group in BC and NS (total=8 clinician groups)

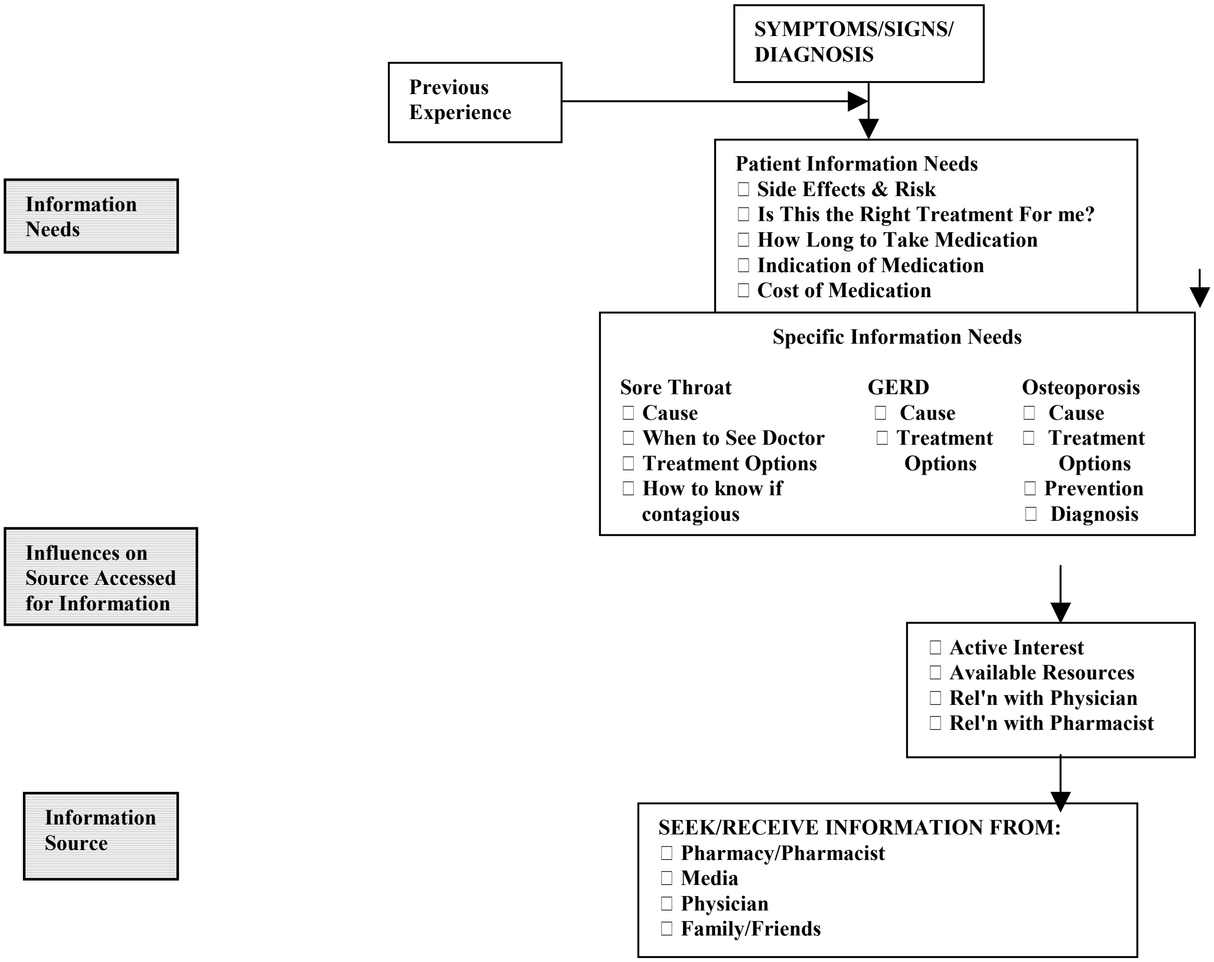
Table 2 describes some of the demographic characteristics of the patients who attended the focus groups.

Table 2: Focus Group Patient Characteristics

Patient Characteristic	Result (N=90 patients)
Female Sex	75%
Mean Age	54 years (SD=19)
Mean Number of Medications	3.7 (SD=3.2)
Mean Number of Visits to Physician	5.0 (SD=4.5)
Mean Number of Visits to Pharmacist	6.3 (SD=6.3)
Working, Retired	29%, 41%

A theoretical model (see Model 1) was developed to depict the relationship between the three research questions. This model describes how the information needs of the patient are influenced by the patient's previous experience and by their diagnosis. Depending on the type of medical condition, a patient's medical needs may also vary. Finally, who a patient seeks information from is mediated by a number of factors including: 1) the interest of the patient, 2) the resources the patient feels they have, 3) the patient's relationship with their physician, and 4) the patient's relationship with their pharmacist.

Model 1: Influences on Patient Treatment Information Needs



Question 1: Patient Medication Information Needs

The first research question related to determining the general medication information needs of patients. Five main themes emerged. These included 1) Side Effects & Risk Information, 2) Is This the Right Treatment for Me, 3) How Long to Take Medication, 4) Indication of Medication, and 5) Cost of medication. While there was a fair amount of consistency in the responses generated in all three study regions, there were particular issues that arose in specific groups. For example, within the Chinese Group in BC, there was a general preference for Chinese medicine and these respondents seemed more satisfied with the information and treatments they received from their own Chinese health care professionals.

1) Side Effects & Risk Information:

When asked about what they wanted to know about a medication or treatment, patients, overwhelmingly stated side effects as their first named response. Side effects and risk information was cited in all 11 patient groups. This category also included statements referring to medication contraindication and interactions. Patients thought that information about whether the medication could be taken if pregnant, was suitable for children, or if there were any other precautions that needed to be taken, should be provided. As well, there were statements relating to a desire to know how a prescribed medication would interact with other medications, food, and alternative medications.

> *But this I think doctors should tell patients when they prescribe a medication that you could have a reaction and if you do, get in touch with them immediately or stop taking the medication. NS2*
>
> *I trust my doctor, I take his word for it and all I want to know is if there is going to be any side effects. NS3*

2) Is this Medication Right for Me?

Patients were interested in knowing whether the medication prescribed for them was the most appropriate for them personally vs a medication that could have been prescribed to anyone with that condition. In almost every group, there was mention of wanting to know what their other available options were. This included both non-pharmacological and alternative remedies. Patients raised questions about the differences between generic vs brand name medications and also wanted to know whether what was being prescribed was the newest or most up-to-date option for them.

> *I'd want to know if I really needed it- if I'm not taking medication, if it would go away on it's own. ON1*
>
> *Probably if there are options. Most doctors don't give you options, they just say this is what you are taking.ON4*
>
> *I'd like to know if my doctor knows alternative medicines as well as the regular medicines because my experience has been that I tell him that I may have some vitamin to cure something, he'll look at me and say what is that? He doesn't know. And I feel that I have to be my own doctor so that I can get help from all the different doctors and I wish they would know about each others' medicines. BC2*

3) How Long Do I Have to Take the Medication?

Patients wanted to know about the duration of time they should be on a medication, how long it would take a medication to work, and if there were any long-term consequences to taking the medication over a long period of time.

> *One thing I wondered about is the length of time you're supposed to take it before you get a check on that particular medication. I've been taking some for quite some time, the doctor hasn't arranged for me to see the doctor who issued it to me so this was a concern. BC3*

4) Indication of Medication

Patients also wanted to know basic information such as the purpose of the medication, what it is used for, and what will it do. Many patients wanted more information about the condition that the prescription had been given for.

5) Cost of medication

Patients were interested in how much the medication would cost and whether there would be any cheaper alternatives. Cost was mentioned in 6 of the 11 groups, with all groups in BC bringing this point up. Only one of the two groups with participants from low-income backgrounds noted cost as an issue (NS and not ON).

Question 2: Patients' Specific Information Needs

In addition to the opening question about general information needs, patients were asked about their information needs for the three conditions that information sheets were developed for. These sheets represented three types of medical conditions: an acute symptomatic condition (sore throat), a chronic symptomatic condition (GERD), and a chronic non-symptomatic condition (osteoporosis). In many cases, patients have expressed their information needs in terms of those relating to the condition itself and not specifically related to medications or treatments. Table 3 describes the main information needs for each type of condition.

Table 3: Information Needs and Source by Medical Condition

Condition	Sore Throat	GERD	Osteoporosis
Information Need	♦ Cause ♦ Treatment Options ♦ When to see doctor ♦ How to know if contagious	♦ Cause ♦ Treatment Options	♦ Cause ♦ Treatment Options ♦ Prevention ♦ Diagnosis
Information Source	Pharmacist	Physician & Pharmacist	Physician

For all three types of conditions, patients wanted to know the cause of the condition as well as what their treatment options were in general. Treatment options were defined broadly by the participants and included prescription medications, OTC medications, and non-pharmacological options. Participants also talked about wanting to know about when to see the doctor and how to know if they were contagious if they had a sore throat. For osteoporosis, patients were also interested in knowing about its prevention and diagnosis. Data for GERD was based on responses from three groups only as this was the final information sheet that was developed. When talking about GERD treatment options, patients were particularly interested in prescription medication options and remedies that they could employ to decrease symptoms (i.e. changing diet).

Question 3: Source of Treatment Information

Patients described seeking treatment information from many sources. Pharmacies or pharmacists, including medication printouts or pill labeling information was the most mentioned current source of drug information for patients. This was followed closely by the media (newspapers, TV, magazines and videos) and then by doctors. Lesser, but still utilized sources of information were friends or family. More than three-quarters of the total number of focus groups, across all jurisdictions thought these four sources were the main current areas where they look for drug information. The internet which was mention in at least two thirds of the focus groups. Lastly, the CPS, alternative practitioners, health centres and drug industry advertising materials were mentioned in 11 to 44% of the focus groups but was not very well represented across the three jurisdictions.

Many patients reported wanting both written and verbal information, so that the printed information supported and reinforced the words of their doctor and information could be reviewed on their own time.

As noted in Table 3, patients felt that there were differences in who they would want treatment information from depending on the condition. For example, patients would go to the pharmacist first for information about sore throats and would go to the doctor first for information about treating osteoporosis. For GERD, there was a consensus that seeking information from both the pharmacist and the physician would be appropriate.

Question 4: Clinician Response to Patients' Information Needs

Physicians and pharmacists were asked about what they thought patients wanted to know about medication treatment options and about the information they were discussing with patients. Physicians and pharmacists both noted many of the same issues raised by patients: side effects, available treatment options, how long to take medication, interactions, indication of medication, and cost. Clinicians did not bring up the issue of whether a prescribed medication was the right choice for a particular patient.

Physicians and pharmacists expressed concern about the amount of information, particularly relating to side effects and other safety issues that they should provide to their patients. It was felt that extra drug information should only be given if it does not contribute to information overload, confusion, or to an increase in patient non-compliance. As well, it was thought that patients might be under-equipped to interpret or contextualize this information.

Clinicians in all three study regions expressed the idea that treatment options and alternatives were important issues to patients and also felt that the degree of desired treatment choice varied with each patient. Self-care treatments, naturopathy, herbal medicines or other treatment options were seen as areas that patients often needed more information. However, it was universally acknowledged that physicians and pharmacists do not have enough time to counsel patients properly or to deal with every information concern a patient might have.

> *Patients don't have, always have the ability to put things in perspective. And everybody's trying to get the patients to be informed. But there's no way they can always make the final decision on things because they just don't have the background or the knowledge and they can't put it in perspective. BCPharm*
>
> *…I think an uneducated patient does not have the ability to decide for themselves or herself what is important what is less important and that's the role of the physician. And the more side effects you put down the more complicated it becomes and at the end of the day the patient goes out with a headache. BCPhys*

Only 1 physician from all of the groups disagreed with the amount of information that health care professionals provided to patients.

> *I think we do a poor job. And you look at the London Drugs now and they give these lectures. They hire a pharmacist or a doctor, they get 300 people coming out to learn about their asthma drugs. People want to learn more then we're telling them. And there's no question about that. BCPhys*

Physicians and pharmacists were also asked to describe the types of information they felt patients wanted to know about the three conditions and what issues they typically discussed with patients. These health care professionals generally felt that patients wanted to know about treatment options, alternative options, and lifestyle adjustments. Much of their discussion focused on how they would assess each of the conditions (asking about frequency of symptoms, etc) and some of the difficulties in getting their patients to take or not take a medication (i.e. antibiotics for sore throat). While clinicians seemed interested in discussing symptomology as a means to help with diagnosis, patients were more focused on finding out what the cause of their condition was.

Clinicians were also asked to relay the types of problems they encountered in giving information to patients. This was contrasted with the positive and negative experiences patients relayed concerning their own instances of receiving therapeutic information**.** The following six themes emerged from the data: 1) Limiting Information, 2) Format of Information, 3) Counseling Patients, 4) Information Vacuum, 5) Information Tools, and 6) Alternative Information. Each of these themes is discussed in more depth below. These six concepts, while interrelated, reflect the main issues that clinicians in this sample were dealing with.

1) Limiting information

There seemed to be no clear consensus among clinicians about how much information patients should be given although clinicians leaned towards favoring less, rather than more information. Some spoke of the need to 'limit content' so that they didn't inadvertently scare their patients off the prescribed treatment. Others maintained that the "content had to be complete".

> *…the preprinted sheets contain almost too much information. You have to be selective on what you are willing to give out" (NS Pharm)*

2) Format of information

Physicians and pharmacists agreed with patients that therapeutic information needed to be simple, clear, easy to read, and with diagrams. They emphasized that the dangers of medications must be given in a context that people would be able to understand, especially so patients understood the frequency of a drug's side effects or other dangers.

3) Counseling patients

Physicians noted some exasperation in having to correct patients of wrong or inaccurate notions about medications or treatments. While patients expressed a strong need to have the listening ear of the clinician, physicians and pharmacists noted that counseling takes time. Physicians stated that they often felt pressure from patients to prescribe a medication even when they knew it not to be in the best interests of the patient. Pharmacists noted the difficulty of giving people information (about adverse effects) and then having them not want to take the medication.

> *I think in general you can persuade patients to accept your word. (BC Phys)*
>
> *A lot of concepts are just hard to convey towards patients"(BC Phys)*

4) Information Vacuum

Pharmacists in particular reported difficulties with wanting to counsel patients but not knowing (or having to guess) what the indication was that led the physician to prescribe the medication in the first place. Pharmacists also felt that they were not adequately compensated for counseling patients so this limits what they are able to do.

> *…a lot of pharmacists complain about counselling in a bit of a void…hoping that you're hitting the mark, but not really sure and covering all your bases so you kind of waste a lot of time trying to zero in on exactly what the medications are for. (NS Pharm)*

5) Information tools
Some clinicians stated that they would enjoy the use of a comprehensive digest to discuss all medication-related issues with patients. Most agreed on the need to tailor information to specific patients and to have material that supports what they are giving to patients verbally. There was a recognized difficulty in making information accessible to patients with low literacy or having people use information without the support of a health professional.

> *…the CPS right at our fingertips, that would be helpful (NS Pharm)*
>
> *A lot of the time that follow-up, written information does have a big impact, so if that would mesh with what you told them verbally… (NS pharm)*

6) Alternative information
Clinicians feel under pressure to provide information on topics they know nothing about (herbal remedies) and they expressed strong feelings about these medications.

According to physicians and pharmacists the most mentioned source patients used when seeking drug information was the drug store or pharmacist. This was mentioned in 6 of the 8 focus groups and indicated that clinicians saw the pharmacist as the key player and the pharmacy as the key location in the provision of drug information. There was agreement that diagnostic information provided by the physicians was important whereas the pharmacist provided more of the product-specific information. There was a fairly common sentiment that sometimes the pharmacist might give 'too much' information and thus scare the patient away from taking the medication.

Clinicians recognized the impact of drug industry materials both in advertising and promoting disease and drug awareness. They were also aware of the influence of the media, especially television, magazines and newspapers in fostering drug awareness. Also high on the list of important information sources was the influence of friends, family and neighbours, in providing drug information followed by the Internet, libraries or public health centres and finally medical journals or public lectures.

When physicians and pharmacists were asked about how (verbal or written) patients would want to receive medication-related information, there was overwhelming consensus that both verbal and written information together could help to reinforce the message being given. While many physicians and pharmacists currently used verbal means of sharing information, the use of simple, easily accessible, focused written information was supported.

Discussion

Patients want a balance of information provided to them, with specific information about why a prescribed medication would be right for them as well as information about side effects, interactions, and costs. When asked about medication information needs specific to the three types of medical conditions, patients tended to be thinking more broadly in terms of the condition itself. This suggests that providing more information about the medical condition may provide a useful context for patients in their evaluation of the medication information that they receive.

Physicians and pharmacists seem to be “in tune with” the kinds of information that patients want to know, yet there is an acknowledged concern that too much information may be detrimental. These clinicians viewed themselves as the purveyors of information and accordingly feel they should be able to use their judgement in what information and how much information is passed on to patients. They also seemed unaware of the need to “personalize” information; that is, that, patients have a need to understand why that medication was prescribed for them in particular. These findings shed light on the important issue of the conflict between the type of information and the depth of information provided to patients. While there appears to be strong commonalties between what patients want and what health care professionals provide, patients desire more information than what health care professionals seem willing to provide.

Physicians and pharmacists reported a tendency to want to sort out inaccurate information and beliefs the patients hold (use of antibiotics, herbal products) and saw a need to screen or temper side effect information. Some believed that side effects should be distinguished as common or rare or have frequencies listed and others thought that it was sufficient to just cover “the main ones” for the patient. Some expressed the belief that a patient may not take the medication if too much risk information is given or that imaginary side effects would emerge if they were mentioned. Some were concerned that the information sheets handed out by pharmacists failed the patient by giving out too much (potentially scary) information.

Pharmacists responded to a depth of issues that people said they wanted. While they were well aware of their professional obligations, their overwhelming feeling was that our medical system is structured in a way that does not reimburse their services for the type of in-depth counseling that is often necessary. They felt that a better reimbursement structure for patient counseling, with the space and time to counsel patients properly, would serve their patients much better. Pharmacists also felt the difficulties of staying on top of new developments in pharmaceuticals and were especially concerned about the information on herbal preparations. Pharmacists recognized that there were some people who want and need more information and others for whom extra information would be a burden. Pharmacists expressed concern about counseling patients and then having them not follow through on advice given.

The overwhelming reaction from physicians is that they feel they do not have enough time to counsel their patients on all the therapeutic options available to them and so they felt compelled to give abbreviated discussions of the prescribed medication. In this light, some welcomed an information sheet which could be used to discuss the important factors involved in making therapeutic decisions. Overall, they acknowledged that information has to be tailored to the specific information needs of the individual patient.

It is a very complicated undertaking to examine clinician’s tendency to supply less risk or side effect information than what patients say they want. The barriers to supplying full and complete information to patients include language barriers, time pressures, and communication difficulties but the perceived patient misuse of information seemed to be the one most mentioned. Further study into the "side effects of telling about side effects" needs to be carried out to determine if there is an adverse impact of drug risk information on health outcomes.

Patients seek out information to medication-related questions in many sources and often this information seeking may have occurred prior to seeing a health care professional. Physicians and pharmacists were aware of the current sources that patients use to find medication information, however often felt that they should be the key source of information. Some physicians expressed concern at the information provided by pharmacists and the information sheets patients receive at pharmacies when filling their prescriptions. Both patients and clinicians viewed written and verbal information, when used together, as meaningful modes of transmitting information.

It was recognized that there were storage and organization problems related written information and that a better system was needed to ensure that the right piece of information went to the right patient at the right time. Finally there was agreement that information, if well designed and in the appropriate written form, had benefits.

Ultimately, the feedback from patients, physicians, and pharmacists in all three test regions helped to ensure that the information sheets developed by the research team was not only based on patients' needs but was also in a format that worked for health professionals (physicians and pharmacists). This conscious effort to include the perspectives of both patients and clinicians is an encouraging step towards the development of meaningful and useful patient information.

Study Limitations

This phase of the Canada Drug Guide study was able to provide valuable information about the general and specific information needs of patients. It was also able to provide some indication of what clinicians think of patients' needs. Despite the promise of these present findings, a number of study limitations should be noted.

First, the participants who attended the focus groups likely represent those that are more interested in patient information needs. As such, their information needs are likely different than those who are not interested in what patients think. Second, for all the variables of interest, sampling to saturation was not completed. This means that there is a likelihood that the views found in some of the groups may be more extreme or idiosyncratic than if the data had reached saturation. Finally, all the participants in the focus groups were given the draft information sheets to comment on <u>at</u> the group. In some groups it was apparent that participants would have benefited from more time to critically read and critique the sheets. Future research could include sending the sheets to participants prior to attending the group.

Implications for Practice

In thinking about the above analyses, it is important to think beyond to how these findings may be relevant to current clinical practice. There are four main practice implications that have arisen from this data:

1) Patients and clinicians need more opportunities to obtain objective, relevant, and individualized patient information.
2) Verbal and written methods of disseminating information, when used in combination may help to reinforce the message being given.
3) Patients tend to be dissatisfied when information is not tailored to their specific needs. Therefore, health care professionals should ask patients what they want to know about medications *before* providing information.
4) Health care professionals who assume that "less is more" when providing information might not be meeting their patients' individual needs for information.

DEMO1=patient first name, DEMO2=patient last name
DEMO3=region patient is from, DEMO4=physician,
DEMO5=pharmacy, DEMO6=guide topic

INTRO
Hello. May I please speak with (**DEMO1**) (**DEMO2**)?

01 Yes
02 No (if no schedule call-back time)

INTR1
Hello, this is (*interviewer's name*); I'm calling from (**DEMO3**). You recently received an information sheet about (**DEMO6**) from (**DEMO4 or DEMO5**) and completed some questions about it. You also indicated that we might call you to talk a bit more about the information sheet. Do you have about 10 minutes now for me to ask you some questions?

01 Yes
02 No (if no, schedule call-back time)

GEND
Interviewer: please note the gender of the person you are interviewing.

01 Male
02 Female

DOB
Could you please tell me your date of birth?
Interviewer: this is the DOB of the person you are interviewing.

DOB ________________ (mm/dd/yy)
99 refused to answer

POST
Could you please tell me what your postal code is?

01 Postal Code ________________
97 Don't know/can't remember
99 refused to answer

Q1A

Was this information sheet for yourself or for someone to whom you are a caregiver?
Interviewer: if caregiver (parent or other), this person must be the decision-maker of the person with the condition.

01 patient
02 parent
03 other

Q1B – **Skip if DEMO4 is blank**

What was the main reason for your visit to (**DEMO4**)?
Was it in relation to…
(*Interviewer: read list of responses*)

01 A Sore throat (**skip to Q1E**)
02 GERD ('heartburn', indigestion, reflux etc.) (**skip to Q1E**)
03 Osteoporosis/Hormone Replacement therapy (**skip to Q1E**)
98 Other ____ (**skip to Q1D**)
99 Refused to answer (**skip to Q1D**)

Q1C – **skip if DEMO5 is blank**

What was the main reason for your visit to (**DEMO5**)?
Was it in relation to…
(Interviewer: read list of responses)

01 Filling a prescription
02 Needing an over-the-counter medication
03 Wanting to talk to the pharmacist
97 Don't know/can't remember
99 Refused to answer
98 Other
____

Q1D

Was (**DEMO6**) discussed during the visit?

01 Yes
02 No

Q1E
Was this a new or recurring problem?
(*Interviewer: Make sure patient knows you are referring sore throat, heartburn, or osteoporosis*)

01	New
02	Recurring
03	Concerned – not yet diagnosed
99	Refused to answer

Q2
How did you obtain the information sheet on (**DEMO6**)?

01	physician/pharmacist provided
02	receptionist/pharmacy staff provided
03	patient requested
04	nurse provided
97	don't know/can't remember
98	other ____

Q3A – **Skip if DEMO4 is blank**
How was the information sheet used by your doctor?
(*Interviewer: Please read the responses – can choose more than one response*)

01	The doctor discussed it with me
02	The doctor gave it to me to take home and read
03	The doctor did not discuss it with me
04	The nurse discussed it with me
05	Was presented as part of a study
97	Don't know/can't remember
98	Other ________________________________

Q3B – **Skip if DEMO5 is blank**
How was the information sheet used by your pharmacist?
(*Interviewer: Please read the responses – may choose more than one response*)

01	The pharmacist discussed it with me
02	The pharmacist gave it to me to take home and read
03	The pharmacist did not discuss it with me
04	Was presented as part of a study
97	Don't know/can't remember
98	Other ________________________________

Q4A
I would like you to think about the information sheet on (**DEMO6**) that you received.
How would you rate the usefulness of the information for you? Would you say it was:
(*Interviewer: Please read list of responses*)

01 Extremely useful
02 Very useful
03 Moderately useful
04 Slightly useful
05 Not useful at all

Q4B
How would you rate the presentation of the information sheet on (**DEMO6**)?
Would you say it was:
(*Interviewer: Please read list of responses)*

01 very easy to understand (**skip to Q5**)
02 mostly easy to understand (**skip to Q5**)
03 neither easy or difficult (**skip to Q5**)
04 a little difficult to understand
05 very difficult to understand

Q4C
Can you tell me what made it difficult to understand?
(*Interviewer: If possible try to get a specific answer, i.e./ not just "too confusing" etc*)

97 don't know/can't remember
98
98 Why Difficult?
____

Q5
Did the (**DEMO6**) information sheet help you?

01 Yes
02 No **(skip to Q6B)**

Q6
How did the information sheet help you? Would you say it…
(Interviewer: Please read responses, can choose more than one response)

01	Helped you to make a decision about treatment
02	Helped you to understand the doctor’s (or pharmacist’s) reasoning
03	Influenced you to not take treatment
04	Influenced you to take treatment
97	Don’t know can’t remember
98	Other ________________________________

Q6A

To what degree would you say the information influenced your decision about taking medication or treatment?
Would you say it had a:
(*Interviewer: Please read list of responses)*

01	very large influence
02	large influence
03	moderate influence
04	slight influence
05	no influence

Q6B **(skip to Q7 if Q5=1)**

Why didn’t you find the information sheet to be helpful?

01	already knew the information – nothing new
02	too difficult to understand
03	information was not relevant to me
97	don’t know/can’t remember
98	refused to answer
98	other _______________________________

Q7

Do you still have the information sheet?

01	Yes
02	No

Q8

What was the main message you took from the information sheet?

97	Don’t know/can’t remember
98	Main Message

____

____

____

Q9
Had you read about treatment options for (**DEMO6**) prior to this guide?

01 Yes
02 No
97 Don't know/can't remember

Q10
Did the information sheet add anything to what you already knew about (**DEMO6**)?

01 Yes
02 No

Q11
Where did you make your decision about treatment for your (**DEMO6**)?
(*Interviewer: read list of responses – can be in past tense*)

01 In the physician's office
02 In the pharmacy
03 At home
97 Don't know/Can't remember
98 Other ________________________

Q12
With whom did you make the decision about treatment for your (**DEMO6**)?
Interviewer: read list of responses – can be in past tense)

01 With the physician
02 With the pharmacist
03 On my own
98 Other ________________________

Q13
Would you like to make any further comments about the (**DEMO6**) information sheet?

01 No
98 Comments

____
____
____

BYE
(**DEMO1**) this concludes our interview. I would like to thank you for taking the time to answer our questions today. I would like to close by saying as an interviewer I am not permitted to comment about your health. If you have any questions concerning your health or your medicines please contact your family physician.

COMTS
Interviewer please record your initials and any other comments

98 Comments ____________________________ Pt ID#: __________
______________________________________ Guide Date: ___________
______________________________________ Int CO Date: ___________

INT
CO Interview complete
02 Not willing to participate
03 Tel # Not in Service
04 Wrong Tel #
05 Language problems during interview/could not complete
06 Pt away past study timeframe (>10 days)
07 Pt deceased
08 Pt unreachable after numerous attempts (>10 days)
10 Pt too ill to complete interview
11 Pt in hospital
12 Pt did not sign consent

GERD Chart Audit Form

Guide Date: _____________ Audit Date:_____________
dd/mm/yy dd/mm/yy

Physician Name: _______________________ Patient ID: __________

Last Frist

D.O.B.: __________(dd/mm/yy) Gender: [ ] M [ ] F

Date of last visit to physician office: __________ (dd/mm/yy)

A. What GERD **symptoms** are recorded in the chart on the last visit date/guide date? (Please check for each of the symptoms listed)

Reflux ---- [ ] YES [ ] NO [ ] Not recorded Duration of symptom______days
Burning/heartburn [ ] YES [ ] NO [ ] Not recorded Duration of symptom ______days
Belching ---- [ ] YES [ ] NO [ ] Not recorded Duration of symptom ______days
Regurgitation of food (waterbrash) [ ]YES [ ] NO [ ] Not recorded Duration of symptom ______days
Dysphagia (difficulty swallowing) [ ]YES [ ] NO [ ] Not recorded Duration of symptom ______days
Odynophagia (pain on swallowing) [ ]YES [ ] NO [ ] Not recorded Duration of symptom ______days
None [ ]
Other, specify ____

B. **Procedures: (please use most recent test)**
Was an endoscopy done?[ ]Yes --- Date of test: ________ [ ]No [ ]Not Available
Result of test: ____

Barium Meal followed by x-ray [ ] Yes --- Date of test: ______ [ ] No [ ] Not Available
Result of test: ____

Any other procedures? [ ] Yes --- specify: __________________________ [ ] No [ ] N/A

C. **What was the prescribed treatment on day of last visit to physician office?**
(please check all treatment noted) (For guide audits – use date of guide visit)

Antacids
(maalox, tums, rolaids etc.) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Ranitidine (Zantac) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Cimetidine (Tagamet) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A

Famotidine (Pepcid) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Nizatidine (Axid) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Omeprazole (Losec) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Lansoprazole (Prevacid) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Pantoprazole (Pantaloc) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Cisapride (Prepulsid) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Sucralfate (Sulcrate) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Alginic Acid (Gaviscon) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Domperidone (Motilium) [ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Metodopramide (Maxeran)[ ]new [ ] renewal/current [ ] incr [ ] decr [ ] D/C [ ] N/A
Non-Drug measures: [ ] diet [ ] smoking [ ] alcohol [ ] other: _____________
No Treatment [ ]
Other:

D. **Was it recorded that** treatment options were discussed **with patient on the last visit date/guide date?**
[ ] Yes [ ] No [ ] N/A
If yes, please noted the options that were discussed?(Please refer to treatment list noted in part C.)

E. Date that GERD symptoms (ie heartburn) was first presented **(if history is not noted at front of chart must look through chart to first reference of GERD symptoms (from part A.) : (5 year history)**
________________ (dd/mm/yy)

F. Was patient seen by **GI specialist**? (look for referral note in summaries) [ ] Yes [ ] No [ ] N/A

G. **Is this the first recorded visit for this problem?** [ ]Yes [ ]No [ ] N/A
If No, indicate previous treatment prescribed (refer to list of treatment options in part C.)
Please indicate name of drug: **(5 year history)**

H. What **non-prescription (drug and non-drug) measures** have been **tried prior to coming in** (Look in physician notes/summaries)? [ ] None noted **(5 year history)**

For Guide Audits:

I. Was receipt of an **information sheet** noted in the chart? [ ] Yes [ ] No

J. If there was a follow-up visit since the Guide date please note any changes to symptoms, treatment, and any test results: [ ] no follow-up visit

Notes from follow-up visit:

Date of visit: ________________ [ ] Visit not relevant to GERD

Osteoporosis Chart Audit Form

Guide Date: _____________ (dd/mm/yy)   Audit Date: __________ (dd/mm/yy)

Physician Name: _______________________ Last   Patient ID: ________________ First

D.O.B: ____________ (dd/mm/yy)   Gender: [ ] M [ ] F

Date of last visit to physician office: _____________ (dd/mm/yy)   [ ] Yearly physical appointment

A. What osteoporosis **signs or symptoms** are recorded in the chart on the last visit date/guide date?

Fractures ----	[ ] Yes	[ ] No	[ ] Not recorded	How many ________________
Hip pain ----	[ ] Yes	[ ] No	[ ] Not recorded	Duration of symptom_________
Back Pain ----	[ ] Yes	[ ] No	[ ] Not recorded	Duration of symptom _________
Shortened stature ----	[ ] Yes	[ ] No	[ ] Not recorded	Duration of symptom_________
Kyphosis ----	[ ] Yes	[ ] No	[ ] Not recorded	Duration of symptom _________
Lordosis ----	[ ] Yes	[ ] No	[ ] Not recorded	Duration of symptom _________

Other, specify ____

None [ ]

B. Procedures: (auditors: use most recent test(s))

Was a bone density test done? [ ] Yes -- Date of test: _______(dd/mm/yy) [ ] No [ ] N/A

1. What bone was measured? ____________________________________

Result: [ ] Normal [ ] Osteopenia [ ] Osteoporosis

Average Volume: ______ T(Z)-score(SD):_______ % difference: _______ % change: _____

2. Second bone measured? _____________________________________

Result: [ ] Normal [ ] Osteopenia [ ] Osteoporosis

Average Volume: ______ T(Z)-score(SD):_______ % difference: _______ % change: _____

3. Third bone measured? _____________________________________

Result: [ ] Normal [ ] Osteopenia [ ] Osteoporosis

Average Volume: ______ T(Z)-score(SD):_______ % difference: _______ % change: _____

Were any other procedures done? [ ] x-ray [ ] other ___________________________

[ ] No

C. What was the **prescribed treatment** on the day of last visit? (Please check all treatment noted) (Please use guide visit date):

Calcium	[ ] New	[ ] Incr	[ ] Decr	[ ] current/renewal	[ ] D/C	[ ] N/A
Vitamin D	[ ] New	[ ] Incr	[ ] Decr	[ ] current/renewal	[ ] D/C	[ ] N/A
Estrogen (Premarin etc.)	[ ] New	[ ] Incr	[ ] Decr	[ ] current/renewal	[ ] D/C	[ ] N/A

Etidronate (Didronel or Didrocal) [ ] New [ ] Incr [ ] Decr [ ] current/renewal [ ] D/C [ ] N/A
Alendonate (Fosamax) [ ] New [ ] Incr [ ] Decr [ ] current/renewal [ ] D/C [ ] N/A
Medroxyprogesterone (Provera) [ ] New [ ] Incr [ ] Decr [ ] current/renewal [ ] D/C [ ] N/A
Raloxifene (Evista) [ ] New [ ] Incr [ ] Decr [ ] current/renewal [ ] D/C [ ] N/A
Nondrug Measures (list): [ ] Yes ________________________________ [ ] No [ ] N/A
No treatment: [ ]
Other:

D. Was it recorded that **treatment options were discussed** with patient on the last visit date/guide date?
[ ] Yes [ ] No [ ] N/A
If yes, please note the options that were discussed? (please refer to treatment list noted in part C.)

E. Date that Osteoporosis was first diagnosed (if history is not noted noted at front of chart must look through chart for first reference of osteoporosis discussions – go as far back as 5 years ago): ___________________ (dd/mm/yy)

F. Was patient **seen by a rhuematologist**? (look for referral note in summaries) [ ] Yes [ ] No [ ] N/A

G. Is this the **first recorded visit for this problem**? [ ] Yes [ ] No [ ] N/A**(5 year history)**
If No, indicate previous treatment prescribed (please refer to the treatment options in part C):

H. What **non-prescription (drug and non-drug) measures** have been **tried prior to coming in** (look in physician notes/summaries)? [ ] None noted **(5 year history)**

For Guide Audits:

I. Was receipt of an **information sheet** noted in the chart? [ ] Yes [ ] No

K. If there was a follow-up visit since the Guide date please note any changes to symptoms, treatment, and any test results: [ ] No follow-up visit

Notes from follow-up visit:

Date of Visit: _____________ [ ] Visit note relevant to Osteoporosis

____

____

____

____

____

____

____

Sore Throat Chart Audit Form

Guide Date: _____________ (dd/mm/yy)
Audit Date: ____________ (dd/mm/yy)

Physician Name: ____________________ (Last, First) Patient ID: ________________ Gender: [ ] M [ ] F

D.O.B: ____________ (dd/mm/yy) Date of last visit to physician office: _____________ (dd/mm/yy)

A. What sore throat **signs & symptoms** are recorded in the chart on the last visit date/guide date?

Dry cough [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
Throat pain - [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
Coughing up sputum [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
Tender glands around the throat [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
Fever --- [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
Red Throat (erythematous) [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
Pus or exudate [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
Nasal(sneezing, runny nose etc) [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
Loss of appetite [ ] Yes [ ] No [ ] Not recorded Duration of symptom ______days
None [ ]
Other, specify ____

B. **Procedures:**

Was a throat swab done? [ ] Yes [ ] No [ ] N/A
Result of swab: Strep – [ ] positive [ ] negative [ ] other [ ] unknown

C. What was the **prescribed treatment** on the day of last visit? (Guide visit) (please check all treatment noted):

Antibiotic (amoxicillin, cotrimoxazole, Septra Bactrim, penicillin etc.) [ ] Yes [ ] No [ ] N/A
If yes – which one, dose, frequency
____

Non-drug therapy (ie gargling with salt water) [ ] Yes [ ] No [ ] N/A
Cough syrup/ lozenges [ ] Yes [ ] No [ ] N/A
No treatment [ ]
Other _

D. Was it recorded that **treatment options were discussed** with patient on the last visit date/guide date?

[ ] Yes [ ] No [ ] N/A

If yes please note the options that were discussed? (please refer to treatment list noted in part C.)

E. Is this the **first recorded visit for this problem?** [ ] Yes [ ] No [ ] N/A **(1 month history)**

If No, indicate previous treatment prescribed (refer to list of treatment options in part C.):

F. What **non-prescription (drug and non-drug) measures** had been tried **prior to coming in for this visit** (Look in physician notes/summaries)? **(1 month history)** [ ] None noted

For Guide Audits:

G. Was receipt of an **information sheet** noted in the chart? [ ] Yes [ ] No

H. If there was a **follow-up visit since the Guide** date please note any changes to symptoms, treatment, and any test results: [ ] No follow-up visit

Notes from follow-up visit:

Date of Visit: ________________ [ ] Visit not relevant to Sore Throat

Appendix G:
Canada Drug Guide Exit Interview

Name: ___________________________
Interviewer: ______________________
Date of Interview: _________________

Patients Recruited (n): _______
Sore Throat: _______
GERD: _______
Osteoporosis: _______

Patient Selection

1. How were the information sheets distributed in your office or pharmacy?
   Prompt if required: Who was responsible for giving out the information?

2. If a patient came to your office, and you personally were dispensing the sheets, how did you decide whom to give a sheet?

Use of the Sheet

3. How did you use the information sheet with your patients?

4. Was any one of the sheets better or easier to use?
   Sore throat ____
   GERD ____
   Osteoporosis ____

5. Did you think the level of reading material was generally appropriate for your patients who received the sheet?
   Appropriate ____
   Too advanced ____
   Too simple ____

6. Specific numbers on the risks and benefits of therapy were presented on the sheets.
   a) Did you find them useful?

   b) Did they help your patients to understand the issues?

   c) Did the information have an impact on drug use and selection?

7. Did you augment the sheets with additional patient education materials? If so, why?

8. Some participants have found it difficult to distribute and use the information sheets. What were the main barriers for you in using these information sheets in your setting?
   a) Were there problems with the content of the sheets? _________

   b) Was the study methodology too time consuming ? _________

   c) Was it a problem specific to your site/office? _________
      Please explain.

   d) Was there a problem in obtaining patient consent? _________

   e) Other? Please specify.

9. What would make the information sheets easier to use?

Effects on Patient Management

10. Did your management of patients to whom you gave the information sheets differ from your usual management of patients with those conditions? Prompt: If so, how?

11. Did the sheets help you in making treatment decisions with your patients?
    Prompt: Can you explain or give an example?

12. In your usual practice, in what percentage of patients with each of these conditions do you think you would use the sheets?
    Sore throat ____
    GERD ____
    Osteoporosis ____

13. Are there other conditions where you think information sheets would be helpful?

The environmental scan consisted of gathering an array of existing patient-oriented drug information leaflets, examining the nature of this material and to see what, if any, evaluations of this material had been done. Specifically this scan tried to answer:

1. What is already available in Canada in terms of existing consumer drug information that deals with the treatment of Heartburn, Sore throat and Osteoporosis? What is the nature, and quality of this information?
2. What evidence exists around the use of patient oriented pamphlets or information?

Existing patient information and pamphlets on Heartburn, Sore throats and Osteoporosis

An enormous amount of information exists, much of it in self-management pamphlets or on websites. There are many internet sites which have a multitude of links listing disease management information by categories. (The British Medical Journal claims there are over 10,000 health related websites and over 1/3rd of people who access the web do so for health or medical purposes). Much of this material is fairly homogeneous in the kinds of information it offers. A typical pamphlet usually includes:

Description of disease/condition
Typical causes for the disease/condition
Typical duration and outcomes of the condition
Basic self-care procedures
Typical treatments and care (including pharmaceutical therapy)
When you should seek professional medical care

The organizations that deliver consumer drug or health information typically include:

Drug industry or organizations that act as industry surrogates
Disease groups (Osteoporosis society, National Digestive Diseases Clearinghouse, etc)
Health maintenance organizations (HMO's)
Medical Academies, Medical and Pharmacist Associations
Universities, Health institutes, community health agencies
“Virtual” hospitals
Health consumer groups, mostly located in the US

Some general notes on the nature of available patient-oriented Osteoporosis, Heartburn and Sore throat pamphlets

Osteoporosis

HRT in particular and menopausal issues in general present a lot of conflicting types of evidence and conclusions based on that evidence. Typically the information around HRT discusses the risks of cancer and heart disease and the benefits on bone health. In general, the complexity of definition of osteoporosis, the controversial issue of bone density testing and the evidence of hormones, bisphosphonates and the new SERMS such as raloxifene make this a very complicated area to deal with in a pamphlet.

- Much of the information shows bias of its author. (Ie: “Osteoporosis Action Plans” to reduce osteoporosis are promoted by the BC Dairy Foundation gives much useful information but does not disguise its main intent: to encourage milk consumption)
- Much of the information tends to heighten fear, and by ignoring important context, tends to exaggerate risk. (ie: "Osteoporosis is responsible for 1.5 million fractures each year"!) While stripping the ‘facts’ of osteoporosis from its context, much of the available material usually provide suggested avenues (usually pharmacologic) to treat or prevent a woman’s risk.
- Relative, not absolute risk and benefit is reported and this tendency leads to a greater urgency in promoting the use of pharmaceutical interventions. There is little discussion of the relative benefits of many non-pharmacologic treatments such as exercise, calcium consumption, the wearing of hip pads, etc.
- In discussing the bisphosphonates, for example, the pamphlets generally report relative benefits (such as a 50% reduction in hip fractures) and give tips on how to take the medicine.
- In general, many of the usual lifestyle tips and recommendations dominate this literature but consumer information on osteoporosis usually concludes with the catch-all phrase: “talk to or doctor about the best ways for you to protect your bones after menopause”.

Heartburn or GERD (Gastro-esophageal Reflux Disease)

- There are some good self-care documents (with vivid drawings) and tips on how to avoid heartburn. The best of these are decision-oriented and actually lead people through an algorithm starting from easy self-care to more invasive and pharmacologic interventions.
- Most of these recommend lifestyle modification and discuss a range of antacids, H2 antagonists, prokinetic agents and indications for an endoscopy, etc. Efficacy, safety, comparability between agents and costs of the available therapeutic alternatives are not dealt with in much detail.
- Brochures typically cover the anatomy and physiology of the stomach and esophagus, how heartburn can occur, typical symptoms of heartburn, information on when a heartburn sufferer should consult a medical professional, and a variety of lifestyle changes that help ease the heartburn problems. (Ie: raised beds, foods to avoid, etc)

Sore Throat

- Patient information pamphlets available on sore throat typically eschew the use of antibiotics and promote non-pharmacologic, common sense approaches to dealing with sore throats and the common cold.
- Most try to distinguish between sore throat and strep throat. Of note is the CMAJ decision-making guide which assigned points to patient symptoms and then used this score to choose an appropriate therapy (ie: based on the patient’s score you decide to take a culture or prescribe an antibiotic)
- Some web-based materials are available for people with low literacy levels
- Sore throat guides typically say that sore throats are (usually) caused by a virus, will likely go away in 5-7 days by themselves, and will not likely be helped by antibiotics. Patients are advised to rest, drink 8 glasses of water each day, eat good food, take aspirin

or acetaminophen as directed; self-care tips include gargling with salt water, stopping or cutting back on smoking. They recommend seeking further medical advice if: your cold lasts more than 2 weeks, or if you have shaking chills, a fever over 101, or cough up green, yellow, or gray mucus or blood, of if you have chest pain, shortness of breath, earache or a headache with a stiff neck.

- Many patient brochures do not discuss the evidence available of the chances of streptocococcal infection, or risks or side effects of antibiotics, if they are required.

Appendix I;
Evaluation Matrix

Component	Evaluation Questions /Key Issues	Process/Outcome Indicator (s)	Sources of Data	Further Issues
Guide Development	Creation of evidence-based medication treatment guides	• # of treatment guides created	• Drafts of guides • Correspondence (emails) re: debate of the evidence • Bibliography of the evidence for each guide	• Who defines 'evidence-based'?
	Inclusion of input from patients, physicians, and pharmacists during creation of guides	• # of patients, physicians, and pharmacists who attended focus groups • Qualitative information gathered from the focus groups about patient medication information needs	• Focus group transcripts • Focus group facilitator debriefing notes	• Selection of participants- convenience and purposeful • Increased reliability due to use of consistent facilitator and focus group guide; however increased travel costs

Component	Evaluation Questions /Key Issues	Process/Outcome Indicator	Sources of Data	Further Issues
Guide Distribution	Recruitment of physicians and pharmacists to give guides to patients	• # of physicians and pharmacists enrolled	• Study Coordinator enrollment log • Fax list of all those sent study information	• Convenience sampling • Physicians and pharmacists in cities where they are heavily "researched", therefore possibly not as representative
	Guide given to patients by physicians and pharmacists	• # of guides given out	• Database	• Deviation from current clinical practice, so will they remember to give out guide?
	Distribution of osteoporosis guide to seniors via internet	• # of seniors who completed internet feedback questionnaires	• Database	• Response bias- those that respond may not be representative of all seniors • Lack of comparison group

Component	Evaluation Questions /Key Issues	Process/Outcome Indicator	Sources of Data	Further Issues
Guide Assessment	Evaluation of guide influence on patient medication choice	• Patient rating of guide usefulness	• Database	• Timeline-must complete call in 10 days or data not usable
	Completion of chart audits of patients who received guide from physician	• # of chart audits completed	• Database	• Different chart auditors in each city • Lack of information in chart
	Completion of chart audits of control patients not receiving guide from physician	• # of chart audits completed	• Database	• Different chart auditors in each city • Lack of information in chart
	Feedback from physicians and pharmacists about study process	• # of exit interviews completed • Qualitative data from interview	• Notes from exit Interviews • Summaries of exit interviews	• Response bias • Different interviewers in each city

Electronic Dissemination of an Evidence-Based Drug Guide to Seniors: Pilot Test

Prevention
Source BC

Prepared by

Prevention Source BC

For

Canada Drug Guide Project
c/o BC Ministry of Health, Pharmacare

September 1999

Electronic Dissemination of an Evidence-Based Drug Guide to Seniors: Pilot Test

Executive Summary

The Canada Drug Guide Project is developing a series of lay evidence-based drug guides for consumers. As a part of a contract with the BC Ministry of Health, Pharmacare, Prevention Source BC conducted a pilot test of an electronic distribution of one such guide to a sample of Canadians over the age of 55. The purposes of the test were to examine whether electronic dissemination of a drug information resource to seniors was feasible, to gain an idea of whether seniors would read and use such guides, and to gather information from members of the target population (seniors) useful to further development and distribution of such guides.

The sample of seniors was obtained largely through soliciting volunteers through the web site of the Canadian Association of Retired Persons. Of 121 volunteers, 90 sent back the questionnaire for a 74% response rate. Seventy three percent of respondents were female, and 27% were male. The age breakdown was somewhat loaded toward the young elderly:

- under 60, 32%;
- 60 to 64, 30%;
- 65 to 69, 27%; and,
- 70 or older, 10%.

Most participants live in BC or Ontario.

The osteoporosis guide was included in an e-mail letter sent to the sample. It was also placed on the Canada Drug Guide (CDG) Web Site. The e-mail letter explained the pilot test and indicated where to access the web site if desired. Participants were asked to either read the letter as appeared in the e-mail, or to access and read the guide at the CDG web site. They were instructed to respond to a questionnaire one week after the original letter.

Questionnaires were collected via e-mail and analyzed. Key findings include the following:

1. 85% of seniors in the sample access e-mail and the Internet on a frequent basis.

2. A majority (69%) of participants accessed the guide via the CDG web site, as opposed to using the e-mail version.

3. Most participants surveyed (83%) expressed a wish to have access to other Canada Drug Guides in the future.

4. Almost all participants (97%) found the guide relevant to them.

5. A large majority (85%) of participants found the guide very readable and easy to understand, with only two participants reported finding the guide not readable or easily understood.

6. About half (48%) of the participants reported that the guide greatly increased their interest in osteoporosis, and 41% indicated it somewhat increased their interest.

7. Eight participants (9%) reported adopting a new lifestyle practice as a result of reading the guide. Another 14% expressed an intention to adopt new lifestyle practices as a result of the guide. More of the participants (42%) reported that they already practiced many of the preventive measures mentioned in the guide.

8. Participants offered many suggestions for topics for future guides, and a fair number of participants had questions or comments about supplements and medications.

This pilot test reached a relatively small volunteer sample, but offers some information on which to base further research and distribution of information. Some recommendations are made based on the survey, including:

☐ A larger test should be conducted, with a series of fact sheets and a more rigorous method of determining impacts on awareness, knowledge, attitudes, and behavioral readiness;

☐ A means of ensuring a temporal separation for all subjects between receipt of the guide and self-assessment needs to be incorporated into any future research. In the pilot, the presence of the questionnaire on the web site interfered with this;

☐ More demographic data needs to be gathered, such as income, education, current health behaviours and medications;

☐ Future surveys would need to address the issue of an evidence-based approach, specifically, any impacts related to discrimination/consumer awareness among seniors; and,

☐ The CDG web site needs to be completed, and a means of advertising the site needs to be developed.

Background

Distribution of health information to the public is a part of any population health or health promotion strategy. Accurate information in an interesting, readable and easily digestible format can significantly increase awareness, interest and knowledge of members of a target population (UT Centre for Health Promotion, 1993; Green & Kreuter, 1991). In turn, these changes are important precursors to the longer-term process of changing individual and collective norms and practices, and form key parts of most extant models of change used in health promotion and in epidemiology (Gordis, 1996; UT Centre for Health Promotion, 1993). As such, health information is valuable when properly disseminated and when in conjunction with other initiatives.

From 1996 to 1998, Prevention Source BC distributed print information resources to seniors and senior service providers as a part of its mandate from the BC Ministry of Health, Pharmacare. However, over time it became evident that 1) many of the print resources available to seniors were not evidence based, but simply information on various types of medications; and, 2) Pharmacare was concerned about the effectiveness and accuracy of passive distribution of such print resources. In 1998, PSBC was commissioned by Pharmacare to conduct a pilot test involving the electronic distribution of a new evidence-based Osteoporosis guide to seniors. This report documents the findings of that test, which had the following purposes:

1. to examine whether electronic dissemination of a drug information resource to seniors was feasible.
2. to gain an idea of whether seniors would read and use such guides.
3. to gather information from members of the target population (seniors) useful to further development and distribution of such guides.

Method

Treatment

The Canada Drug Guide Project provided us an electronic version of its Osteoporosis Guide. It is a one-page summary of osteoporosis information, relative risks and effectiveness of estrogen replacement and other drug therapies, and information on preventive measures. The guide was inserted into an e-mail in text format, and also placed directly on a new web site prepared for CDG by PSBC (http://www.canadadrugguide.org). An e-letter of explanation was prepared, and invited participants to read the guide either from the e-mail or by going to the CDG web site. A questionnaire was prepared and sent one week after the original e-mail.

Sample

Prevention Source BC placed an ad on the web site of the Canadian Association for Retired Persons during April and May of 1999, providing information on the pilot test and inviting participation. Of 172 persons responding with interest, 121 valid addresses were identified. All of those respondents with valid addresses, all were sent the e-letter and questionnaire. Of these, 90 individuals responded, providing a more than satisfactory 74% response rate.

Most respondents were from British Columbia or Ontario, with a small scattering among other provinces. Almost three quarters (73%) were female, 27% were male. The age breakdown was somewhat skewed toward younger seniors: under 60, 32%; 60 to 64, 30%; 65 to 99, 27%; 70 or older, 10%.

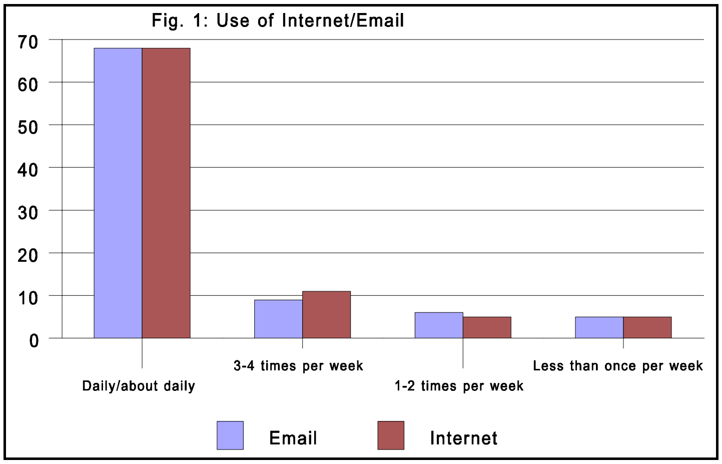


Fig. 1: Use of Internet/Email

Any effort to garner participation in reading guides will produce a biased sample of volunteers. In this specific case participants obviously all have access to and use e-mail. These factors likely produced a sample differing considerably from the general population of seniors. However, this not a substantial problem in that the pilot test examined electronic distribution, and therefore was directed specifically at such a group.

Questionnaire

The 16-item questionnaire (Appendix B) solicited information in five areas:

a) demographics

b) e-mail and web site use

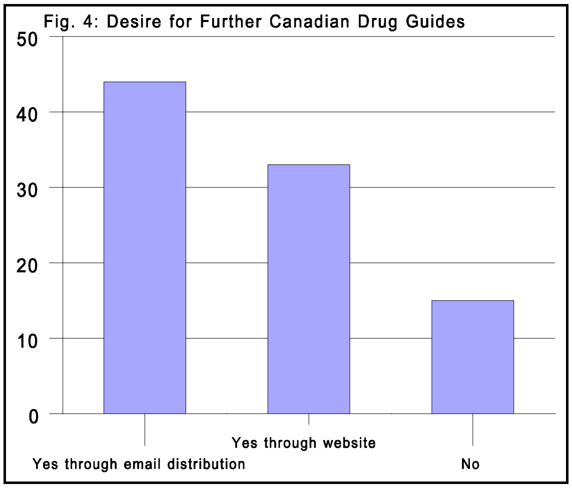
c) readability/appropriateness of the guide

d) response to the guide

e) general suggestions and comments

Participants responded by clicking on response categories, and in some cases by entering responses in their own words. The questionnaire was returned with a single SEND function.

Findings



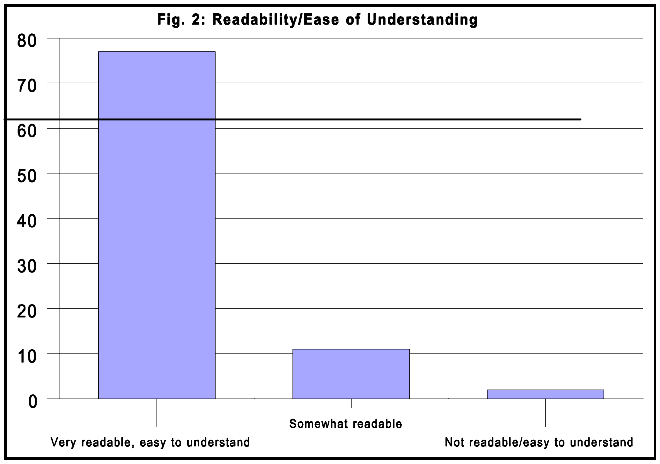
E-mail and Web Site Use

Figure 1 shows responses of the sample when queried about the frequency with which they used e-mail and the Internet. Clearly, the participants are regularly on-line. Over 85% of seniors in the sample (n=79) access e-mail and the Internet at least three or four times a week. Three fourths (n=68) reported using e-mail and the Internet daily or almost daily. Clearly, this sample of seniors is very much wired into both e-mail and the Internet and are likely not casual users of the technology.

Participants were also asked which method they used to read the guide - the e-mail version or the formatted version on the CDG web site. A majority of participants (n=62, 69%) accessed the guide via the CDG web site, as opposed to the e-mail.

Readability/Appropriateness of the Guide

Figures 2-4 show responses to questions about readability and appropriateness of the guide. A large majority (n=77, 85%) of participants found the guide very readable and easy to understand. In fact, only two participants reported finding the guide not readable or easily understood. Almost all participants (n=87, 97%) found the guide relevant to them, with 49 (55%) saying that the guide was very relevant and an additional 38 (42%) indicating it was at least somewhat relevant. And, a large majority of participants surveyed (n=81, 83%) expressed a wish to have access to other Canada Drug Guides in the future. The sample appeared interested in receiving this mode and type of information on health topics, primarily via a web site but with many also asking for e-mail notification.



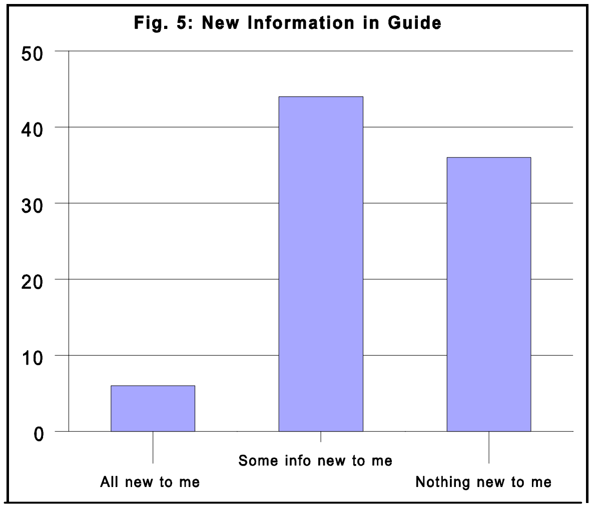


Fig. 5: New Information in Guide
50
40
30
20
10
0
All new to me
Some info new to me
Nothing new to me

Response to the Guide

Figures 5 - 7 display responses to items regarding participants' response to the guide content. First, participants were asked whether the information was new to them. To this 50 participants (61%) responded that at least some information was new. About half (n=43, 48%) of the participants reported that the guide very much increased their interest in osteoporosis, and an additional 37 (41%) indicated it increased their interest somewhat. Eight participants (9%) reported adopting a new lifestyle practice as a result of reading the guide. Another 13 seniors (14%) expressed an intention to adopt new lifestyle practices as a result of the guide. A larger portion (n=38, 42%) of participants reported that they already practiced many of the preventive measures mentioned in the guide

General Suggestions and Comments

Most participant comments fell into one of two areas: Suggestions for topics for future guides, and questions or comments about supplements and medications. Many of the latter were sent directly to representatives of the Canada Drug Guide project.

Topics the participants most wanted to see in future guides, through open responses, are as follows (in order of frequency named):

4. Blood pressure / heart medications (6)

5. Updates on existing osteoporosis treatments (5)

6. Bowel conditions and medications (4)

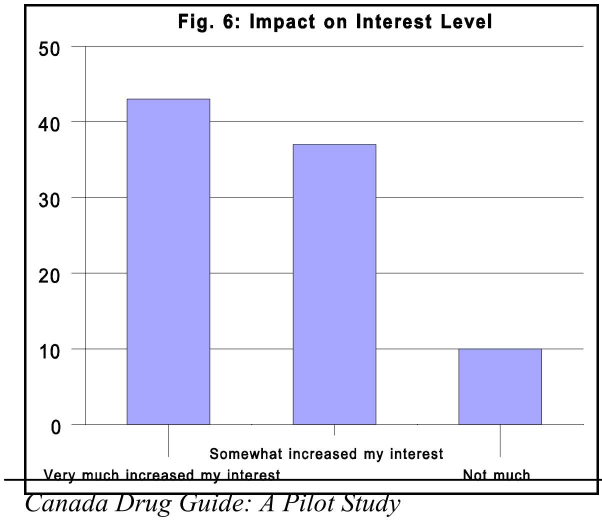


Fig. 6: Impact on Interest Level

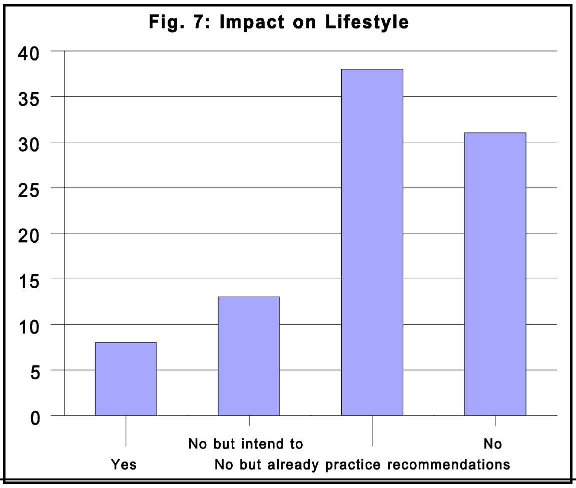


Fig. 7: Impact on Lifestyle

7. Diabetes treatments (3)

8. Natural and herbal medicines (3)

Other topics for drug guides mentioned by single individuals include:

- Information on osteoporosis for young women
- Sexuality and medications
- Weight control
- Pain relievers
- Asthma
- Hiatus hernia
- Hypoglycemia

Other comments and questions from the sample included:

This is a very good source of information (5)

I already do many of the preventive measures (4)

The survey was difficult to complete (3)

Is it really worth taking estrogen? (2)

I have attended an osteoporosis clinic (2)

I have osteoporosis and am taking Fosomax (2)

I have been putting it off - this has increased my awareness (1)

What is it about some types of calcium not being effective? (1)

I wish my physician had recommended HRT and supplements (1)

This is good. I showed it to my wife (1)

I will ask for a bone density test (1)

Discussion

Any discussion of the findings has to be done cautiously given that this was a small survey, given to a sample of volunteers, and which solicited a limited amount and breadth of self-report information. However, in considering this mode of information delivery, some interesting observations can be noted.

First, a cadre of seniors who are on-line and interested in health information certainly exists. This cadre will inevitably grow in coming years with continued diffusion of the technology into older populations and with the aging of the population itself. Clearly, electronic distribution needs to be thoroughly pursued as an option.

Second, this particular type of information, as it is formatted, generated quite a positive response in terms of its usefulness and appropriateness. The sample found it clear and easy to follow, an important first step in dissemination of information.

Third, the resource appears to have heightened awareness in the sample, and led to some increase in readiness to change. Nothing more than this could reasonably be expected of a single, short print resource. In conjunction with an ongoing effort using many channels (e.g., professional and peer education, social marketing, and policy), such information may well produce the desired end-stage in prescribing/drug taking values and practices. Unfortunately, efforts are often hit and miss, stop and start. And, if we know anything about health information, we know a single dose in and of itself is simply insufficient.

Several questions arise from the pilot test. For example, how feasible is it to generate a large network of seniors on-line? To what extent is such an approach “preaching to the converted,” in that the profile of the health-promoting adult - urban, educated, and middle to high income - may fit many of this sample? What longer-term effects might repeated dissemination of such resources have on attitudes toward medications in general? What kinds of follow-up might be most effective in spurring the motivation of recipients to try new practices? As more guides are produced, it would be useful to monitor use by seniors and ask additional questions about effects of the material. This could be used as an opportunity to begin building a network, as seniors visit the CDG web site and make individual requests. In fact, an effective outlet for seniors is needed - if the information is going to be provided, opportunity needs to exist for them to ask further questions and to receive further information.

Several recommendations are offered based on the experience and findings of the pilot test:

1. A larger test should be conducted, with a series of fact sheets and a more rigorous method of determining impacts on awareness, knowledge, attitudes, and behavioral readiness.

2. A means of ensuring a temporal separation for all subjects between receipt of the guide and self-assessment needs to be incorporated into any future research. In the pilot, the presence of the questionnaire on the web site interfered with this.

3. More demographic data needs to be gathered - income, education, current health behaviours and medications, for example.

4. A future survey, if conducted, needs to address the issue of the evidence-based approach. Does such an approach have any impacts related to discrimination/consumer awareness among seniors?

5. The CDG web site needs to be completed, and a means of advertising the site needs to be developed.

Undoubtedly, the technology continues to surge. Common sense alone indicates there are a growing number of seniors who use the Internet on an increasingly frequent basis. It is not a question of whether to use the electronic medium to provide information, it is how, where, when, and what. Further investigation using the CDG web site could help answer these questions.

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Alan Cassels; Patient and Clinician Perception of Patient Medication Information Needs, to the Therapeutic Products Program Working Group on Product Monograph Development, Health Protection Branch, Health Canada, Ottawa, Ont. March 14, 2000

Alan Cassels, Naked in the Pharmaceutical Marketplace: The Canada Drug Guide Project and research in the world of consumer drug information, British Columbia Ministry of Health Policy Rounds, Victoria BC, April 20, 2000

Alan Cassels, Suffering from Unbalanaced Information?: Try treating yourself with a strong dose of evidence-based drug information. Building Bridges Conference: Creating an Integrated Approach to Women's Health, Victoria, BC, April 30, 2000.

Alan Cassels; "Medicalizing Women's Health: Knowing the risks and benefits", presentation as part of Bridging the Gap to Women's Health Conference, Victoria, BC, June 9, 2000.

Posters:
Kalpana Nair; Patient and Clinician Perception of Patient Medication Information Needs presented at the American Society of Clinical Pharmacology and Therapeutics, Los Angeles, California, March 14, 2000

Michelle Proctor-Simms, Canada Drug Guide Project poster at the Health Fair; Queen Elizabeth II Hospital in Halifax; December, 1999.

APPENDIX L:

AMERICAN SOCIETY FOR CLINICAL PHARMACOLOGY AND THERAPEUTICS

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FOLLOW ALL INSTRUCTIONS ON OTHER SIDE BEFORE TYPING ABSTRACT.

A. **PRESENTING AUTHOR** (Must appear as first author on abstract)

CHECK ALL THAT APPLY TO FIRST AUTHOR:

Full Name & Highest Degree(s) Kalpana M. Nair, M.Ed ☐ **ASCPT MEMBER** ☑ **NONMEMBER** ☑**TRAINEE**

Institution: Centre for Evaluation of Medicines, St. Joseph's Hospital Address: 25 Charlton Avenue East, Suite 708

City, State, Zip Hamilton, Ontario, L8N 1Y2 Phone (905) 522-1155 x4919 Fax (905) 528-7386

B. **ATTACH $ 30 CHECK (ONE PER ABSTRACT), INTERNATIONAL MONEY ORDER, OR COMPLETE THE CREDIT CARD (VISA, MASTERCARD, AMERICAN EXPRESS) SECTION ON BACK OF FORM FOR PROCESSING FEE.** (Check must be U.S. funds drawn through a U.S. or Canadian bank and made payable to ASCPT).

C. **Indicate the ASCPT SCIENTIFIC SECTION to which you would like this abstract assigned for review (see instructions on back of this form) and enter 3-letter abbreviation below:**
TEA_____________ _ _ _ _

D. **SCIENTIFIC TOPICS (please CIRCLE ONE topic from EACH of the lists provided)**

CIRCLE ONE therapeutic area which best describes your abstract:

A) Analgesiology
B) Anesthesia
C) Allergy
D) Cardiology
E) Child Development
F) Dermatology
G) Drug Abuse
H) Endocrinology
I) Gastroenterology
J) Geriatric Clin. Pharm.
K) Gynecology
L) Headache
M) Hematology (nonmalignant)
N) Hypertension
O) Infectious Diseases
P) Immunology
Q) Inflammation
R) Neuropharmacology
S) Oncology
T) Ophthalmology
U) Pediatrics
V) Pulmonary
W) Pregnancy/Obstetrics
X) Psychopharmacology
Y) Renal
Z) Rheumatology
AA) Teaching Clinical Pharmacol.
BB) Drug/Toxicology Monitoring
CC) Vaccines
DD) Other ___________

CIRCLE ONE topic area which best describes your abstract:

A) Adverse Drug Reactions
B) Biostatistics/Methodology
C) Clinical Study Results
D) Drug Development
E) Drug Transport
F) Drug Utilization Evaluation
G) Drug-Disease Interactions
H) Drug-Drug Interactions
I) Formularies
J) Metabolism
K) Pharmacoeconomics/Outcomes
L) Pharmacoepidemiology
M) Pharmacodynamics
N) Pharmacogenetics
O) Pharmacokinetics
P) Pharmacometrics
Q) Molecular Therapeutics
R) Regulatory Affairs
S) Surrogate Markers
T) Other _Education__________

E. **SUPPLY THREE KEY WORDS FOR INDEXING THIS ABSTRACT** (key words should be nouns only, with adjectives following if necessary [e.g., interaction, acute drug]; do not use abbreviations; avoid general and redundant words such as *drug* and *pharmacology*).

Patient Education
Methods, Qualitative
Patient Medication Information

F. ☐ **UNABLE TO GIVE ORAL PRESENTATION**

G. **PRESENTING AUTHOR's SIGNATURE REQUIRED**
If accepted for oral presentation, I agree to have this presentation audio taped and available for purchase.

____
Presenter's Signature

H. **SIGNATURE of TRAINEE's SPONSOR REQUIRED**
(if trainee is presenting author)

____
Trainee Sponsor's Signature

START ABSTRACT HERE. STAY WITHIN BORDER.

PATIENT AND CLINICIAN PERCEPTION OF PATIENT MEDICATION INFORMATION NEEDS. K. Nair*, MEd, L. Dolovich*, PharmD, M. Levine, MD, J. Gray, MD, K. Mann*, PhD, J. McCormack*, PharmD, A. Cassels*, MPA, Canada Drug Guide Project, Centre for Evaluation of Medicines, Hamilton, Ontario, Canada.

This study used qualitative methods to examine patients' and clinicians' perceptions of the medication information patients need to make informed therapeutic decisions.

Using criterion sampling, 11 patient, 4 physician, and 4 pharmacist focus groups were generated in 3 regions of Canada. A semi-structured interview guide was used to collect data on broad drug information issues and more specifically about 3 medical conditions-sore throat, heartburn and osteoporosis. QSR NUD*IST was used to organize the data. At least two research team members analyzed the data.

Patients' information needs and the initial sources they sought for health information and guidance differed depending on the condition (osteoporosis-physician; sore throat-pharmacist; GERD-physician or pharmacist). Patients strongly desired education on all treatment options, benefits, and risks, including side effects. In contrast, some clinicians raised concerns about the feasibility and impact such complete disclosure might have on patient care. Members of all patient focus groups were concerned about who they could trust to provide health information.

Understanding patients' information needs will ultimately help clinicians provide more meaningful and useful education.

Spell out any abbreviations in the title/author/affiliation lines for printed program:

____
____
____

SAMPLE TO SHOW STYLE:

DEFICIENT C-OXIDATION OF NICOTINE. N.L. Benowitz, MD, D. Sachs, MD, and P. Jacob, III, PhD, Div. of Clin. Pharmacol., S.F. General Hospital, Univ. of Calif., San Francisco, and Palo Alto Center for Pulmonary Disease Prevention, Palo Alto, CA

In most people, nicotine is extensively (on average, 80-90%) metabolized to . . .

Appendix M:
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