



PODS

Patient-Oriented Discharge Summary

November 2014



Ontario

Toronto Central Local Health
Integration Network



OpenLab is a design and innovation shop dedicated to finding creative solutions that transform the way health care is delivered and experienced.

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Executive Summary



PODS co-design workshop, February 2014

The period following discharge from hospital is a vulnerable time for patients. The transition of care from hospital to community or from hospital staff to patient self-management can result in adverse events leading to avoidable ED visits, hospitalizations and poor patient outcomes. Clearly communicating important information that patients need to know the moment they leave the hospital seems sensible, but is often not done in practice for a variety of reasons.

With the support of the Toronto Central

Local Health Integration Network (TC LHIN), OpenLab (formerly CICC) undertook an eight-month project to:

- 1 Assess the current state of how discharge information is communicated to patients
- 2 Understand the patient experience with discharge information and instructions
- 3 Work with patients and clinicians to design a patient-oriented discharge summary (PODS) based on best practices in information design, graphic design and patient education

OpenLab involved patients throughout the project: it talked to them in the hospital,

followed them home, conducted focus groups and included them as part of project team. The team learned that patients do not need to know everything contained in the current discharge summaries, just the few important things they should understand and could act on. And the clinicians involved in the project agreed. This set of information boils down to the following five essential elements:

- 1 Medication instructions
- 2 Follow up appointments with phone numbers
- 3 Normal expected symptoms, danger signs, and what to do
- 4 Lifestyle changes and when to resume activities
- 5 Information and resources to have handy

OpenLab developed a prototype PODS (see below) to reflect these five essential elements, and in consideration of design factors such as plain language, typography, visual aids and simplicity of layout. The prototype PODS also gives consideration to the cognitive processes involved in information processing and retention by including white space in the margin for patients to jot down their own notes, which has been found to improve information recall.

PODS is considered a “prototype” because it is very much a work in progress, and the team hopes that through use, PODS will be further fine-tuned and improved upon by the user community. PODS is freely available to all organizations to adopt and adapt, based on their local circumstances. For organizations that would like to create their own, the team encourages them to not start from scratch, but to learn from what has already been uncovered through this project. These lessons have been packaged into a set of guidelines and checklists at the end of this report. Finally, PODS complements other existing initiatives aimed at making hospital discharges more patient-centered, including the TC LHIN’s Standardized Discharge Summary project, the TC LHIN’s Quality Initiative that has identified patient experience focusing on communication of information to patients during transitions as one of its big dot system indicators, and the HealthLinks’ initiative on ensuring that patients see their primary care provider within 7 days of hospital discharge.

_____ 's Care Guide

I came to hospital on dd/mm/yy and left on dd/mm/yy

 my own notes

I came in because I have _____



Medications I need to take

morning noon afternoon night

Name

Dose

What it is for



How I might feel and what to do

I might feel

What to do

Go to Emergency if:



Changes to my routine

Activity (i.e. dietary, physical)

Instruction



Appointments I have to go to

Go see _____ for _____ on dd/mm/yy at 00:00 am/pm

Location: _____ ☎ _____ booked



Where to go for more information

For medication instructions call/go to pharmacist ☎ _____

For _____ call/go to _____ ☎ _____

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Importance of Discharge Information

The period following discharge from a hospital is a vulnerable time for patients. The transition of care from hospital to community or from hospital staff to patient self-management can result in adverse events leading to avoidable ED visits, hospitalizations and poor patient outcomes. Studies show that adverse events can result from ineffective communication, limited patient literacy for reading drug labels or inability to recall medical instructions¹⁻⁵. As a result, the Avoidable Hospitalization Expert Panel (chaired by Ross Baker) in its 2011 report to the Ontario Ministry of Health and Long-Term Care⁶ identified poor communication of discharge instructions to patients as an important care gap, with the following root causes:

- 1 Patients do not understand medical terms
- 2 Patients are not fluent in English
- 3 Patients cannot memorize verbal instructions
- 4 Patients are too stressed at time of illness to absorb information

Studies have shown that 40-80 percent of the information patients receive is forgotten immediately⁷ and nearly half of the information retained is incorrect.⁸

The problem is even more pronounced for patients with language barriers, particularly in ethnically diverse communities such as Toronto, where over 60% speak languages other than English or French at home, and 4.5% of residents report having no knowledge of either of Canada's official languages.⁹ Individuals with language barriers face significant challenges in navigating the health care system, leading to poor self-reported health,¹⁰ increased medical errors,¹¹ poor compliance with therapy and follow-up¹² and increased costs,¹³ among other outcomes. Even for people with no language barrier, the ability to obtain, process and understand basic health information and services needed to make appropriate decisions – known as health literacy – varies from person to person.¹⁴ An estimated 55% of Canadians between the ages of 16 and 65 have low health literacy, and only 12% of those above the age of 65 have adequate health literacy skills.¹⁵ Poor health literacy leads to poor health outcomes, especially among the elderly, those with limited education and chronic diseases, as well as new immigrants with a language barrier.^{15,16}

TC LHIN POPULATION FACTS

- 1 2.6 million people live in Toronto, the fifth largest city in North America. 1.15 million people live within TC LHIN.
- 2 2.4 million daily commuters come into Toronto.
- 3 54% of patients in TC LHIN hospitals and 55% of patients who see TC LHIN family physicians reside in other LHINs.
- 4 An estimated 32% of the population is 22 to 44 years old and 14% is aged 65 years and older. Seniors will account for 14.8% of the LHIN's population by 2016.
- 5 41% of residents are immigrants, 8.3% arrived in Canada between 2001 and 2006.
- 6 170 languages and dialects are spoken in Toronto and 4.5% of the population reports no knowledge of either official language.
- 7 There are 53000 Francophones in Toronto (9.2% of Ontario's Francophone population). Many are recent immigrants and/or visible minorities.
- 8 Toronto has one of the largest and most diverse Aboriginal populations in Canada. Approximately 1.5% to 2% of TC LHIN residents are Aboriginal and 50% of the Aboriginal population is under the age of 25.
- 9 Just over one quarter of the population is low income.

Current State of Discharge Communication

INFORMATION GIVEN TO PATIENTS

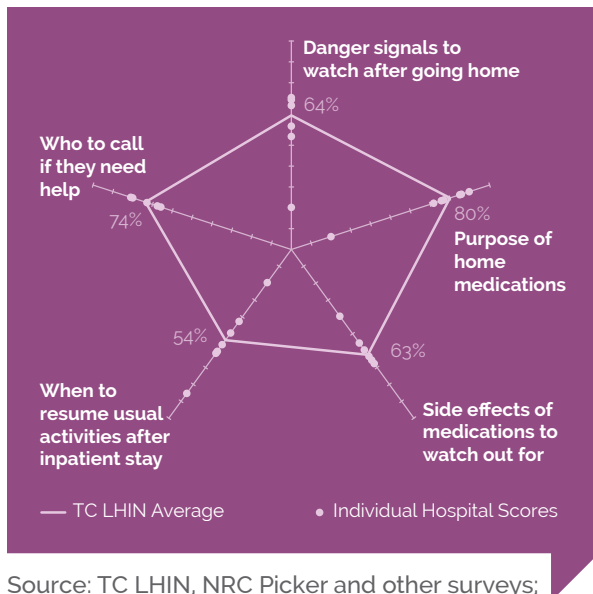
In reviewing discharge summaries from different hospitals, it was evident that these were information dense documents laden with technical language meant mostly for the patient's primary care provider. These documents were not well suited for use as tools to transmit critical information from hospital to patient at time of discharge. In the world of discharge summaries, patients are almost thought of as messengers in the transport of documents from hospital to primary care provider, a practice previously performed by fax machines. Given that the hospital discharge event and ensuing primary care appointment might be separated by many days, this practice seems less than ideal in the absence of effective patient self-management strategies.

There is also considerable variation across hospitals, and even from department to department within a hospital, in terms of how discharge summaries and packages are assembled and delivered. Discharge packages in certain hospital departments (e.g. elective surgeries) are generally quite good and are often available in multiple

languages. In other areas, such as general internal medicine, where patients arrive unexpectedly and are often very complex, there is generally room for improvement. Furthermore, these are precisely the types of patients for whom effective communication of medication and care instructions is likely to make a difference for their health and avoid unnecessary return to the hospital.

PATIENT EXPERIENCE WITH DISCHARGE COMMUNICATION

Patient satisfaction survey results across TC LHIN hospitals in 2012/13 highlight several challenges in how discharge information is currently communicated to patients. The majority of discharged inpatients in TC LHIN indicate that they know the purpose of their home medications (80%). However, the largest gap is in knowing when to resume usual activities after an inpatient stay (54%), followed by knowing what side effects of medications to watch out for (63%), what danger signals to watch after going home (64%) and who to call if help is needed (74%). Particularly striking is the variation in the patient's experience from hospital to hospital (see chart).



Source: TC LHIN, NRC Picker and other surveys; survey samples from Q1, Q2, Q3 2012/13 depending on hospital.

Throughout the project, the team had the opportunity to interact with many patients and their caregivers, 56 in all. Among the issues and concerns commonly alluded to were:

READINESS TO RECEIVE INSTRUCTIONS

Patients identified many barriers to understanding and following instructions, the most prominent being exhaustion, 'being in a fog', feeling overwhelmed and in some instances, feeling overjoyed to be going home. Many indicated that while they felt like they understood what was being communicated to them at time of discharge, they often had difficulty remembering what to do when they got home. "We were given verbal instructions about what we

should do in certain situations, for suture care, etc. Printed instructions would have been more helpful because we were exhausted by the end of her stay; thus we were not taking in the verbal instructions very well. If something is important enough to mention at discharge, it really should also be written down." - caregiver

READINESS TO ASSUME CARE MANAGEMENT RESPONSIBILITIES

Some patients indicated that they felt unprepared to leave the hospital or were concerned that they would not be able to manage on their own once they got home. "Yes, I too was surprised at how quickly I was discharged from the hospital with very little information and absolutely no follow up." - patient

RELEVANCE OF INFORMATION

Patients wanted to know information that was relevant to them and that they could act on. They consistently mentioned the following types of information as being most important:

- 1 Medication instructions
- 2 Follow up appointments with phone numbers
- 3 Normal expected symptoms, danger signs, and what to do
- 4 Lifestyle changes and when to resume activities
- 5 Information and resources to have handy

Information considered important to patients

"The only thing that I wish I had known before leaving was exactly who to call under what circumstances." - caregiver

"Specialists often say to fax a note and they will call, but they don't. I find it helps to give patients the specialist's number and instructions to call if they haven't heard from them within a week's time. If they don't have those guidelines and the specialist doesn't follow up, that follow up appointment will never happen." - resident

INVOLVEMENT OF FAMILY AND CAREGIVER

Family members and caregivers play a significant role in a patient's life. This role

becomes even more significant after an inpatient stay, where family members and caregivers take on the task of supporting the patient with their follow up care.

Patients expressed a desire to have discharge instructions relayed to them in the presence of the caregiver that will be helping with post-discharge care. "My primary caregiver is my husband. He has been amazing! From first recognizing that I needed to go to the hospital then spending a good part of every day with me. He is exhausted physically and emotionally." - patient

"What a terrible start to the day. (My husband) has his own agenda of what I should and should not be doing. Here again instructions from the hospital would have been helpful. Cross words have been spoken and I know neither of us is at fault. I seem to cry very easily." - patient

Design of PODS

Previously, the TC LHIN's Standardized Discharge Summary project had developed a discharge summary template that is being rolled out across TC LHIN hospitals to provide consistency in information sharing between hospitals and primary care providers. The PODS project was initiated in an attempt to develop a tool that would ultimately complement the Standardized Discharge Summary, but focused specifically on information most relevant and actionable for patients, presented in an easily understandable and usable form. In the hospital, PODS was envisioned to be a tool that could aid clinician-patient communication and used as part of a teach-back process. At home, PODS was envisioned to be an elegantly simple care guide, something that could occupy prime space on one's refrigerator perhaps.

Over a period of eight months, OpenLab (formerly CICC) used a combination of methods to understand the types of information patients want to and should know, and the design features that would make PODS usable for a wide range of patients and yet practical for providers to implement.



PODS co-design workshop, February 2014

Data collection methods included a literature review, interviews with providers, observation and focus groups with patients and their caregivers. The team sought out and engaged patients across a wide spectrum of abilities. Particular emphasis was placed on involving patients that are generally harder to reach, such as those with language barriers, low health literacy and mental health issues. In addition to the traditional methods highlighted above, the team employed special techniques to more deeply understand the patient experience and pain points, and to involve patients and their caregivers throughout the design and prototyping of PODS. These included:



Patient experience mapping exercise, Nov. 2013

- 1 A patient experience mapping exercise that brought together health care providers, patients, and community service providers to capture patient interactions as they transition from hospital to community
- 2 A take-home information collection kit known as a cultural probe¹⁷ was given to patients in the process of being discharged. Each kit contained a personal journal, disposable camera and 'postcards from home' to document their post-discharge life. The probe provided the team with a window into how discharge information might be used in the real-world context when patients arrive home
- 3 A co-design workshop where teams of patients, health care providers and designers worked together to build the initial concepts for PODS
- 4 A stress test of an early version of the prototype with a group of Cantonese-

speaking patients (through an interpreter) and a group of patients with mental health issues

- 5 At the other extreme, an online discussion with a virtual patient and caregiver panel made up of generally health literate and internet-savvy patients and family members
- 6 Finally, a usability test of a paper-based version of the prototype within the real-world clinical setting across three different hospital sites

In designing PODS, the team gave careful consideration to the existing body of knowledge and best practices surrounding the effective design of patient education tools and materials. It has been shown that verbal communication alone is not as effective as when it is combined with other modes of communication.¹⁸

Visual aids have been shown to be particularly useful to non-English speakers and patients with low health literacy scores, who tend to have poorer recall of medications and instructions¹⁹. It is also known that written materials are more effective when they are simple, use larger fonts, and focus on essential information²⁰. It is also helpful to use short words and sentences, writing directly



Cultural probe kit.

to the reader, listing important points in list format, and using left justification so there is even spacing between words. An illustrated medication schedule has also been shown to be effective²⁰.

The literature is consistent with the advice from patient education specialists on the team, as well as the feedback from patients. That is, PODS should be written in plain language, use large fonts, include illustrations of care and medication schedules, and include headings that are meaningful to the patient. In addition, the prototype PODS also gives consideration to the cognitive processes involved in information processing and retention by including white space in the margin for patients to jot down their own notes, which has been found to improve information recall.²¹

PODS is considered a "prototype" because it is very much a work in progress, and the team hopes that through use, PODS will be further fine-tuned and improved upon by the user community. PODS is freely available to all organizations to adopt and adapt, based on their local circumstances. Some organizations might choose to implement PODS electronically, while others might go the low-tech route. Some organizations have discharge planners and coordinators who might be helpful resources in the delivery of PODS to patients, while others might choose to rely on other professionals to do so. These decisions are inherently local, and must take into consideration the organization's existing capabilities, culture and change management requirements. "We can provide a list of patient meds in a grid format with days of the week and times of day. We use our judgement to give this to patients. It is not standard practice." - pharmacist

"A discharge form in 'plain English' should be standardized."
- patient

"This is a great piece. You guys are doing an awesome job."

This would have saved me so much anxiety and fear of doing something wrong when I was discharged. I didn't want to bother my doctors and went on a hope and prayer. Even my home care people weren't always sure of what to do. Again this would be a great step forward in easing patients' fears especially senior citizens. Great work. Thanks for caring!"
- patient

_____ 's Care Guide

I came to hospital on dd/mm/yy and left on dd/mm/yy

 my own notes

I came in because I have _____



Medications I need to take

morning noon afternoon night

Name

Dose

What it is for



How I might feel and what to do

I might feel

What to do

Go to Emergency if:



Changes to my routine

Activity (i.e. dietary, physical)

Instruction



Appointments I have to go to

Go see _____ for _____ on dd/mm/yy at 00:00 am/pm

Location: _____ ☎ _____ booked



Where to go for more information

For medication instructions call/go to pharmacist ☎ _____

For _____ call/go to _____ ☎ _____

Designing Your Own Pods

Given the amount of research and feedback incorporated in the design of the PODS prototype, the team recommends that hospitals use the prototype and refine it over time as needed as opposed to designing something from scratch. However, for those hospitals inclined to build their own, the team offers the following set of guidelines, which have been constructed based on the research and learnings gathered through this project. This section begins with advice on how to assess your current discharge documents that are provided to patients. It then provides guidelines on the content of what should be in PODS, how to design PODS, and the process of delivering PODS to the patient. The section concludes with a single tip sheet summarizing all the guidelines.

ASSESSING CURRENT DISCHARGE INFORMATION FROM THE PATIENT'S PERSPECTIVE

Every hospital cares that their patients transition home smoothly and want to provide patients with the tools they need to feel comfortable with their care in the time following discharge. In order for this to happen, hospitals should assess

their current discharge processes and documents that are given to patients.

A helpful tool to use when assessing discharge documents is the discharge summary evaluation form developed during this project. It can be found in the Appendix. It is important to have staff and your patient education department review the process and documents; however, it is even more important to have them reviewed by patients and their families. If the hospital has a patient and family advisory group, that is a great place to start.

Once there is an understanding of the current documents and processes, the hospital can then use the provided guidelines on content and design to help improve their own documents and the guidelines on process to help ensure that the documents are delivered to patients in a way that encourages effective communication.

CONTENT CONSIDERATIONS

Below are guidelines on what content **SHOULD** and **SHOULD NOT** be present on PODS.

A WHAT HAPPENED IN THE HOSPITAL

Do let the patient know the name of their medical condition. Include the dates of hospitalization

B MEDICATION SCHEDULE

Do include medications in a chart. Include the name of the medication, what it is for, the total dose, and checkboxes of when to take the medication (with symbols to represent time of day).

Do not Include a picture of the medication (could come in multiple forms), side effects (will deter patients and that information can be included in other sections), a number of pills (doses can come in multiple forms).

C FOLLOW UP CARE SCHEDULE

Do list referrals for follow up appointments with names, numbers, and dates. Make sure the patient knows whether they need to book the appointment or if it has been booked for them.

D WHAT IS NORMAL (HOW YOU MIGHT FEEL), WHAT POSSIBLE DANGER SIGNALS ARE AND WHAT TO DO FOLLOW UP CARE SCHEDULE

Do provide a sense of how normal

symptoms can change to danger signals (e.g. reduced energy can become dangerous if they can't get out of bed), include what the patient should do if they experience symptoms.

When applicable (for mental health patients) include a note that if you recognize danger signs noted in your safety or crisis plan, to please refer to the plan for coping strategies and actions.

E WHEN TO RESUME VARIOUS ACTIVITIES AND OTHER LIFESTYLE CHANGES

Do provide this with actions of the lifestyle change to be made or approximate times for when an activity may be resumed.

F LISTS OF RELEVANT RESOURCES AND POINTERS TO ADDITIONAL INFORMATION

Do provide a link to resources maintained by your CCAC (when the patient has a relevant diagnosis). Refer patients to the patient education department of their hospital. Provide the number for the hospital helpline or any other known relevant helplines.

DESIGN CONSIDERATIONS

Below are format and design guidelines for creating PODS so that it is more meaningful to patients.

A PLAIN AND SIMPLE WORDING

A hospital admission, especially an unplanned one, can create chaos for patients, their families, and their support network. A simple and clear document is essential. You should use plain language and headings that are meaningful to the patient. Keep it short.

B USE LARGE FONTS

12 point is a minimum, serif fonts work better

C DESIGN FOR PATIENTS WITH LANGUAGE BARRIERS BY INCLUDING ENGLISH AND ANOTHER LANGUAGE

If provided in other languages, the document should present information in English and the patient's language of choice side by side as much as possible. Options are to use a dual column or double-sided format. At a minimum, major headings should be provided in multiple languages and sections should be numbered.

D USE VISUAL COMMUNICATION

It is helpful to include visuals for patients with language barriers and low health literacy. The following visuals are recommended: a medication chart, symbols for time of day in the medication chart, symbols for section headings.

E INCLUDE WHITE SPACE

Provide white space for patients, family, or caregivers who may want to take notes on PODS.

F USE THE ACTIVE VOICE AND A POSITIVE TONE

This is clearer for patients to understand and makes it easier to act on instructions.

G WRITE TO THE PATIENT AND THEIR CAREGIVER

Use the words you, I, we, us, to make your document more personal. Refer to your readers in the first person.

PROCESS CONSIDERATIONS

Below are guidelines to keep in mind for the process of delivering and going through PODS with the patient.

PODS is one element in the larger discharge process. This section is specifically about the elements of the discharge process that relate to delivering PODS to the patient. Some general guidelines to keep in mind during the larger discharge process are to treat the patient and their family and caregivers as a part of the team and to let them know what is going on in the discharge planning process, what they can expect, and when they can expect to be discharged (even if this is not a specific date, but rather a time window). Success has been shown when hospitals follow up with the patient via a phone call post-discharge within 48-72 hours. In general, best practice discharge planning guidelines should be followed²².

A DELIVER PODS IN THE PRESENCE OF THE FAMILY OR CAREGIVER

Patients are very overwhelmed and have trouble absorbing information. It is best to deliver PODS when the family or caregiver is present. PODS is as much for them as it is for the patient. Family plays a key role in transitioning a patient home. Remember that family is whoever the patient defines to be their family.

B PROVIDE MULTIPLE COPIES

The role of the family and caregiver is significant in the post-discharge phase. Three copies of PODS should be provided (1 for the patient, 1 for the family or caregiver, and 1 to go with the standard discharge

summary to the community based health care provider(s).

C USE AN INTERPRETER

If there is a language barrier it is critical to use an interpreter when delivering PODS.

D ENCOURAGE QUESTIONS

Patients often want to appear to be "good patients" and may not ask questions even when they don't understand. Encourage questions and note taking. Tell them about the notes section on PODS. Remind them that they and their health care provider will also receive a standard discharge summary with more details about test results and other treatments that occurred in hospital.

The DIY PODS Checklist

Use this tip sheet as a checklist to evaluate and design your own PODS.

00 ASSESS WHAT YOU HAVE

- Is it accessible?
- Is it understandable?
- Is it usable?

01 CONTENT CONSIDERATIONS

- Simple description of the medical condition
- Medication chart
- Follow up appointments with phone numbers
- Normal expected symptoms, danger signals, and what to do
- When to resume activities and other lifestyle changes
- Applicable resources

02 DESIGN CONSIDERATIONS

- Use larger fonts
- Use plain language relevant to the patient
- Use visual and written communication
- Include white space for note-taking
- Include multiple languages (if appropriate)

03 PROCESS CONSIDERATIONS

- Delivered in the presence of family or caregiver
- 3 copies provided (1 for patient, 1 for family/caregiver, 1 to accompany standard discharge summary)
- Interpreter used (if applicable)
- Conversation encouraged

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Appendix

DISCHARGE SUMMARY EVALUATION FORM

Circle one number for each statement: strongly disagree strongly agree

Information is easy to find	1	2	3	4	5
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Comments:

Information is easy to understand.	1	2	3	4	5
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Comments:

I understand what I have to do based on the	1	2	3	4	5
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information in the document.

Comments:

I would have liked more information about: _____

I would have liked less information about: _____

What may have helped improve my ability to find the information? _____

What may have helped improve my ability to understand the information? _____

What may have helped improve my ability to use the information? _____

Where would visuals or images have been helpful? _____

Other comments and suggestions: _____