

Cancer Care Ontario
Action Cancer Ontario

Measuring Patient Experience with Cancer Symptom Management: A Collaborative Survey Design Process

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Ontario
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Outline

- Background
- Survey Re-development Process: Working Group
 - 1) Define Domains
 - 2) Question Development
 - 3) Usability Testing
 - 4) Approval
 - 5) Implementation
- Results
- Lessons Learned/Next Steps

Cancer Care Ontario (CCO)

Cancer Care Ontario is an Ontario government agency that drives quality and continuous improvement for cancer, chronic kidney disease and access to care for key health services

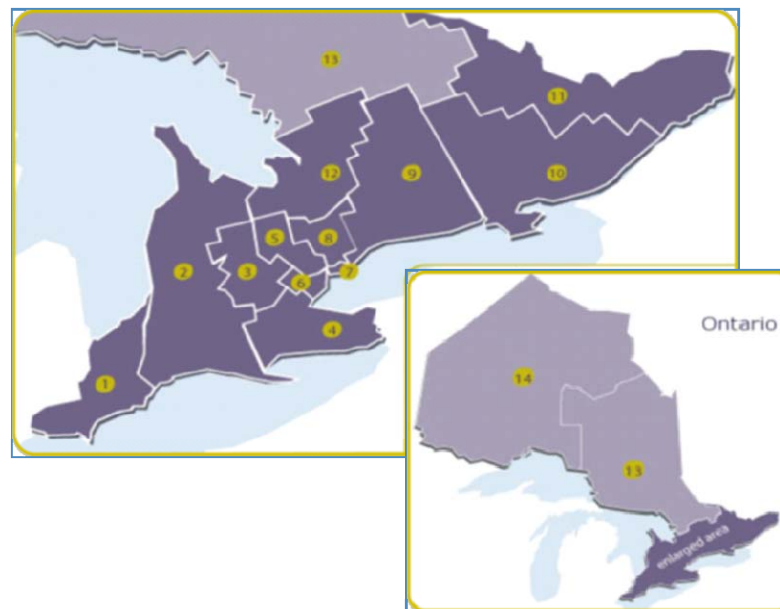
Ontario

Population:

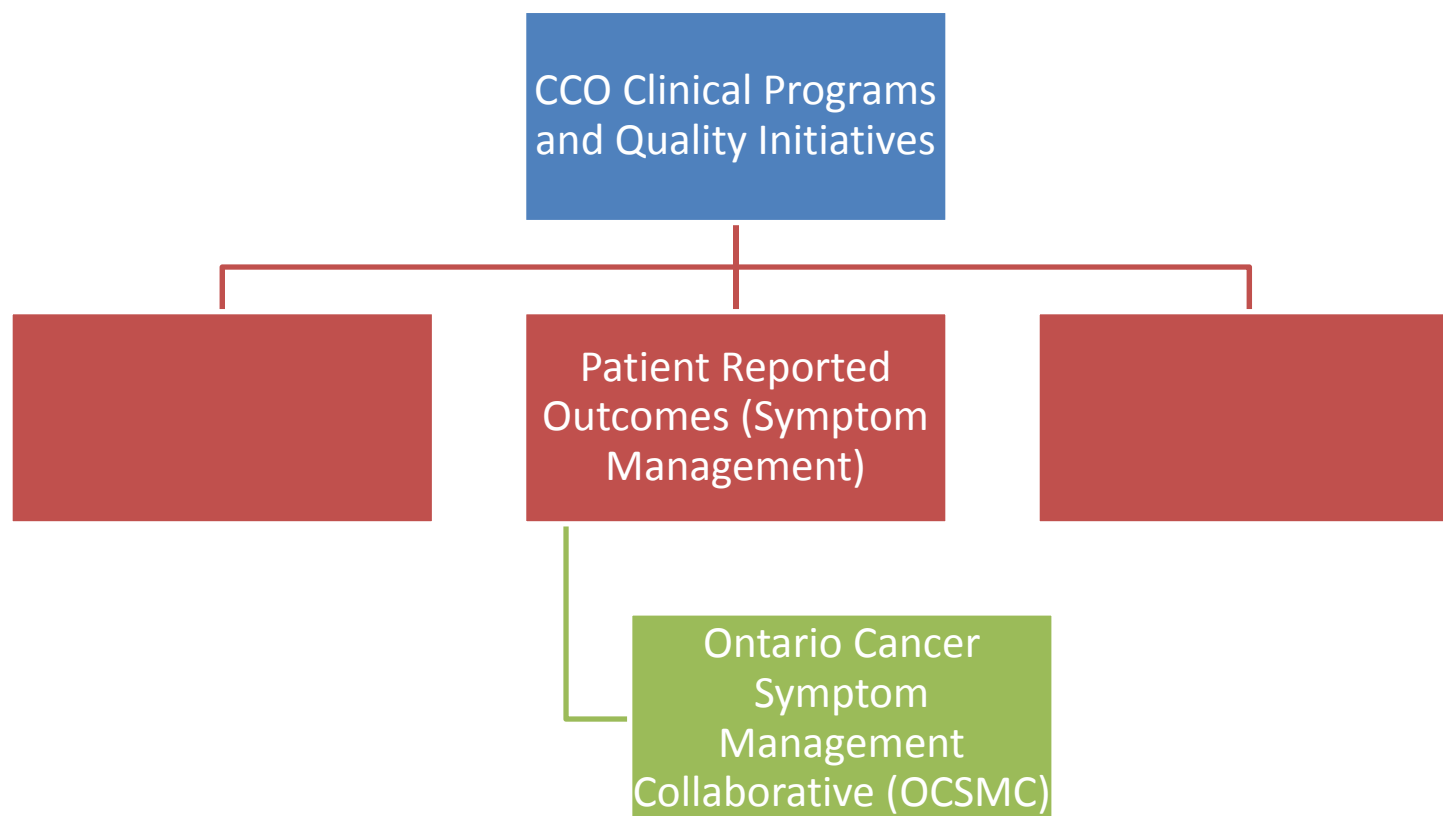
13.5 million people

Distributed cancer system:

14 Regional Cancer Programs and one central cancer agency: CCO



Cancer Care Ontario (CCO)



- Representation from all 14 regional cancer programs
- Improve patient experience across cancer journey:
 - Symptom identification - PROs **Edmonton Symptom Assessment System (ESAS)**
 - Symptom Management (**clinician response**)

ESAS (Edmonton Symptom Assessment System)

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Edmonton Symptom Assessment System
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness (Tiredness = lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness (Drowsiness = being sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression (Depression = feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety (Anxiety = feeling nervous)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing (Wellbeing = how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem (for example constipation)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name _____
Date _____ Time _____

Completed by (check one):
 Patient
 Family caregiver
 Health care professional caregiver
 Caregiver-assisted

ESAS-R
Edmonton Symptom Assessment System

BODY DIAGRAM ON REVERSE SIDE



Background: Symptom Management Patient Experience Survey

- Purpose of annual survey (2010)
 - Patient feedback: **ESAS/Symptom Management**
 - Public reporting (Cancer System Quality Index)
- Rationale for Revision
 - Responding to regional needs
- Goals:
 - Compare/benchmark
 - Reflect reality
 - Actionable – QI plan

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Insert Hospital Logo

Managing Your Symptoms – How are We Doing?

This survey is **voluntary** (you do not have to fill this out) and **ANONYMOUS** (we will not know who filled this out). Please do **NOT** complete this survey if today is your **FIRST** visit to this centre.

PART A: Please tell us about your **experience** using the **symptom assessment form** (sometimes called **“ESAS”**, **“SAAC”**, or the **“kiosk”**). Your answers can help make improvements to the care we provide you and future patients.

1. I know **why** I should complete my **symptom assessment form** (ESAS/SAAC/kiosk).
 Yes
 Somewhat
 Not at all

2. I know **when** I am supposed to complete my **symptom assessment form** (ESAS/SAAC/kiosk).
 Yes
 Somewhat
 Not at all

3. The **symptom assessment form** (ESAS/SAAC/kiosk) **helps me report my symptoms** to my health care team.
 Yes
 Somewhat
 Not at all
 I have never filled in a symptom assessment form (ESAS/SAAC/kiosk)
 I usually do not have symptoms to report
If some of your symptoms are not listed on the symptom assessment form, please tell us which symptoms are missing: _____

4. When I **report** symptoms that concern me on my **symptom assessment form** (ESAS/SAAC/kiosk), my health care team and I **talk about them**.
 Always
 Sometimes
 Rarely/Never
 I have never filled in a symptom assessment form (ESAS/SAAC/kiosk)
 I usually do not have concerning symptoms to report
Other comments?: _____

5. If I **do not always complete** (or have **trouble** completing) my **symptom assessment form** (ESAS/SAAC/kiosk), it is **because** (select **all** that apply):
 My health care team does not always look at it
 There are problems with the computer/kiosk (e.g. not working, difficult to use)
 I am called into clinic before I can complete it
 The 0-10 rating scale is confusing for some of the symptoms
 I do not know what the symptom assessment form is
 Other (please explain): _____
 I do not have any problems completing the symptom assessment form (ESAS/SAAC/kiosk)

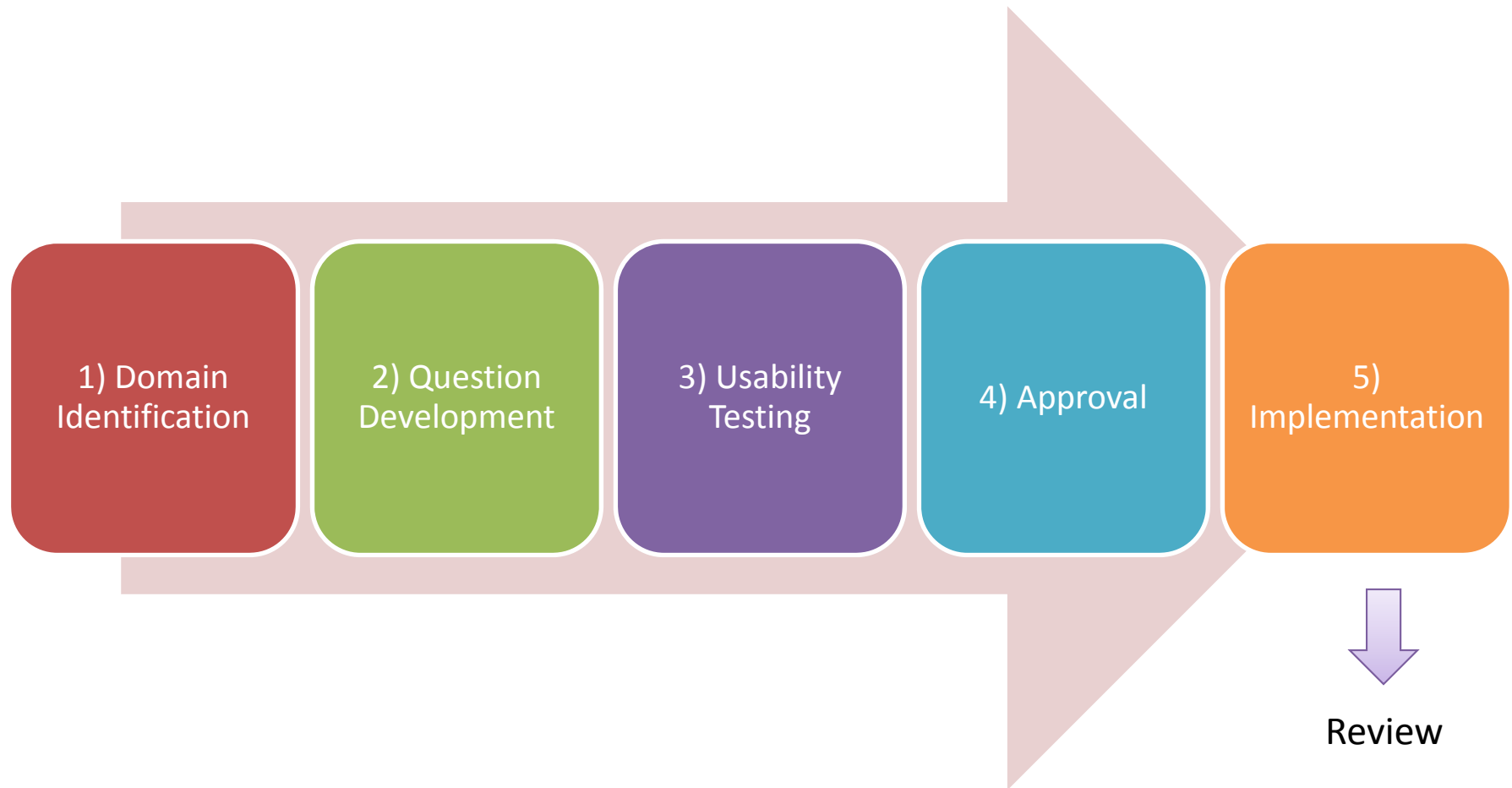
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OCSMC → Create Working Group

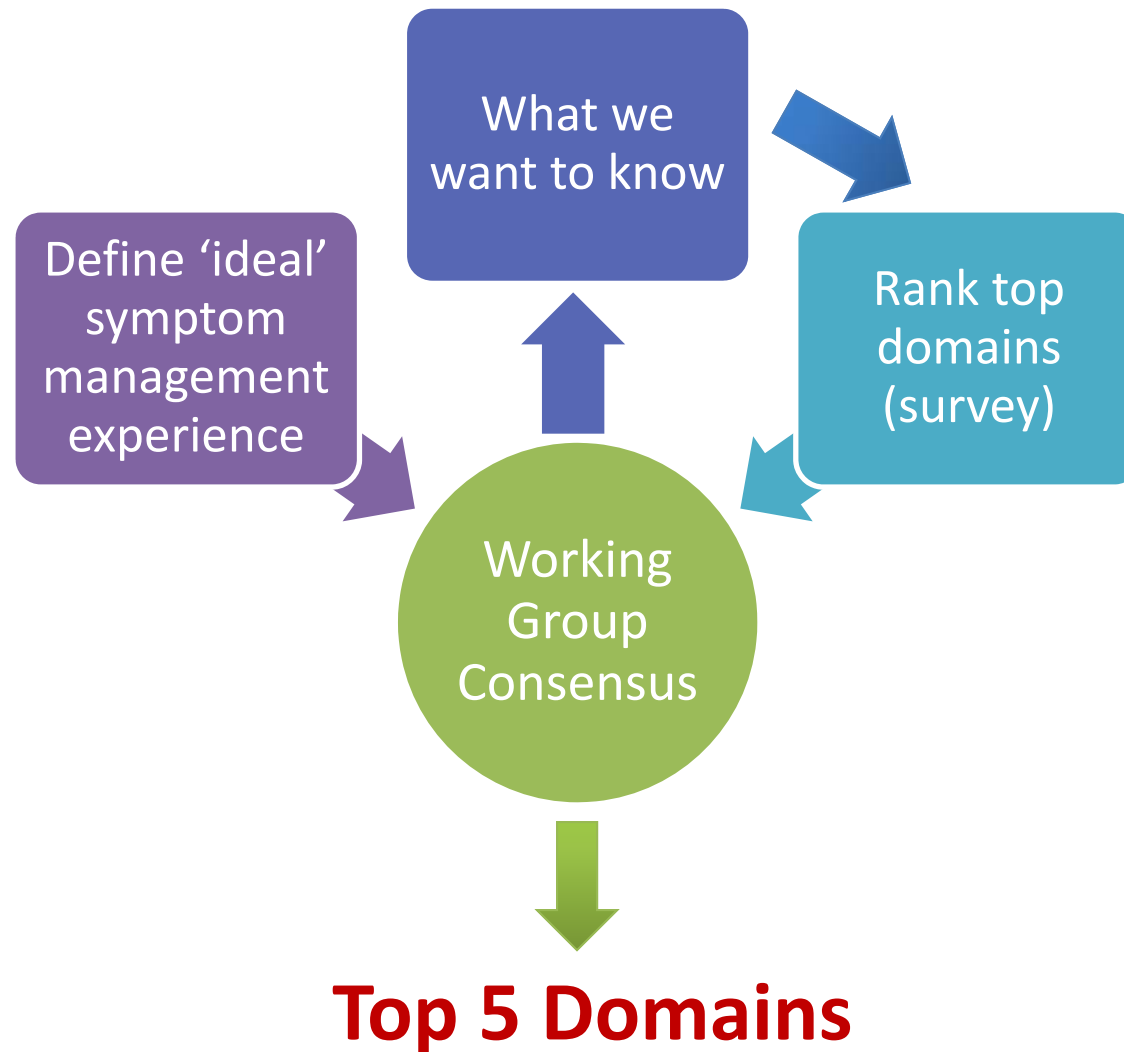
- Voluntary
- 18 members (representing 12 regions)
 - Patient and family advisors
 - Clinicians
 - Administrators
 - Researchers
- 2.5 months



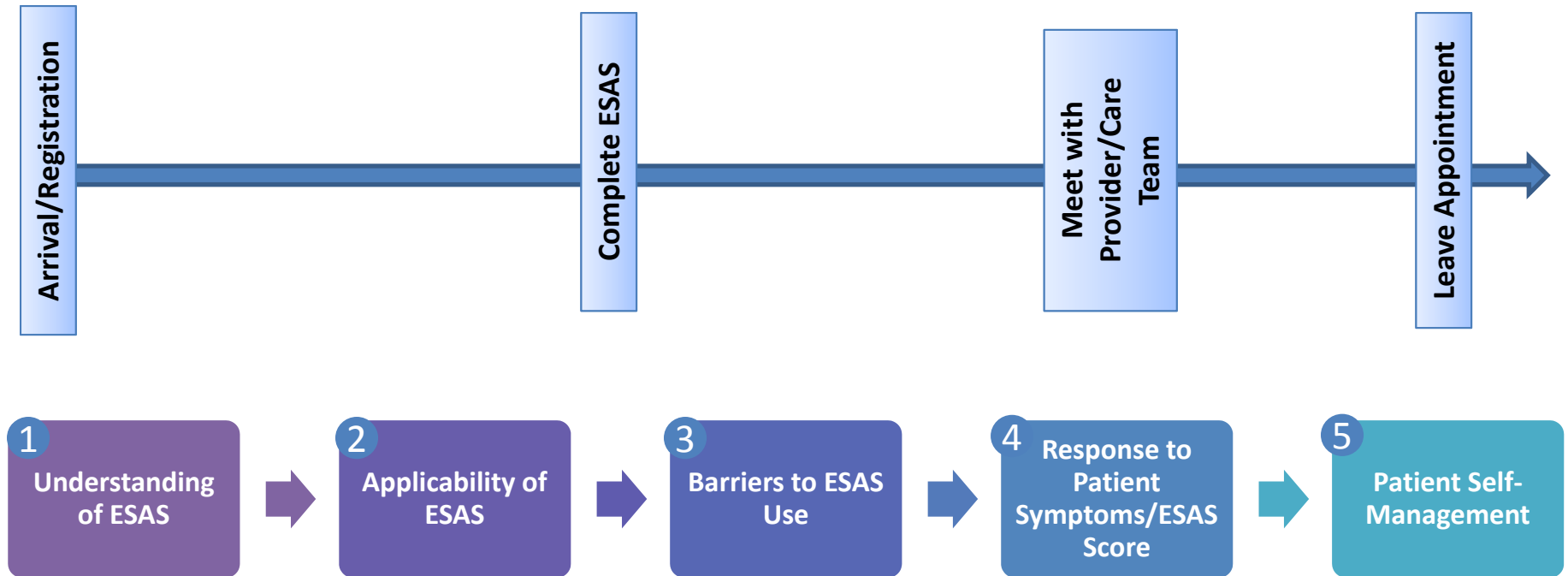
Survey Re-design: 5 Stage Process



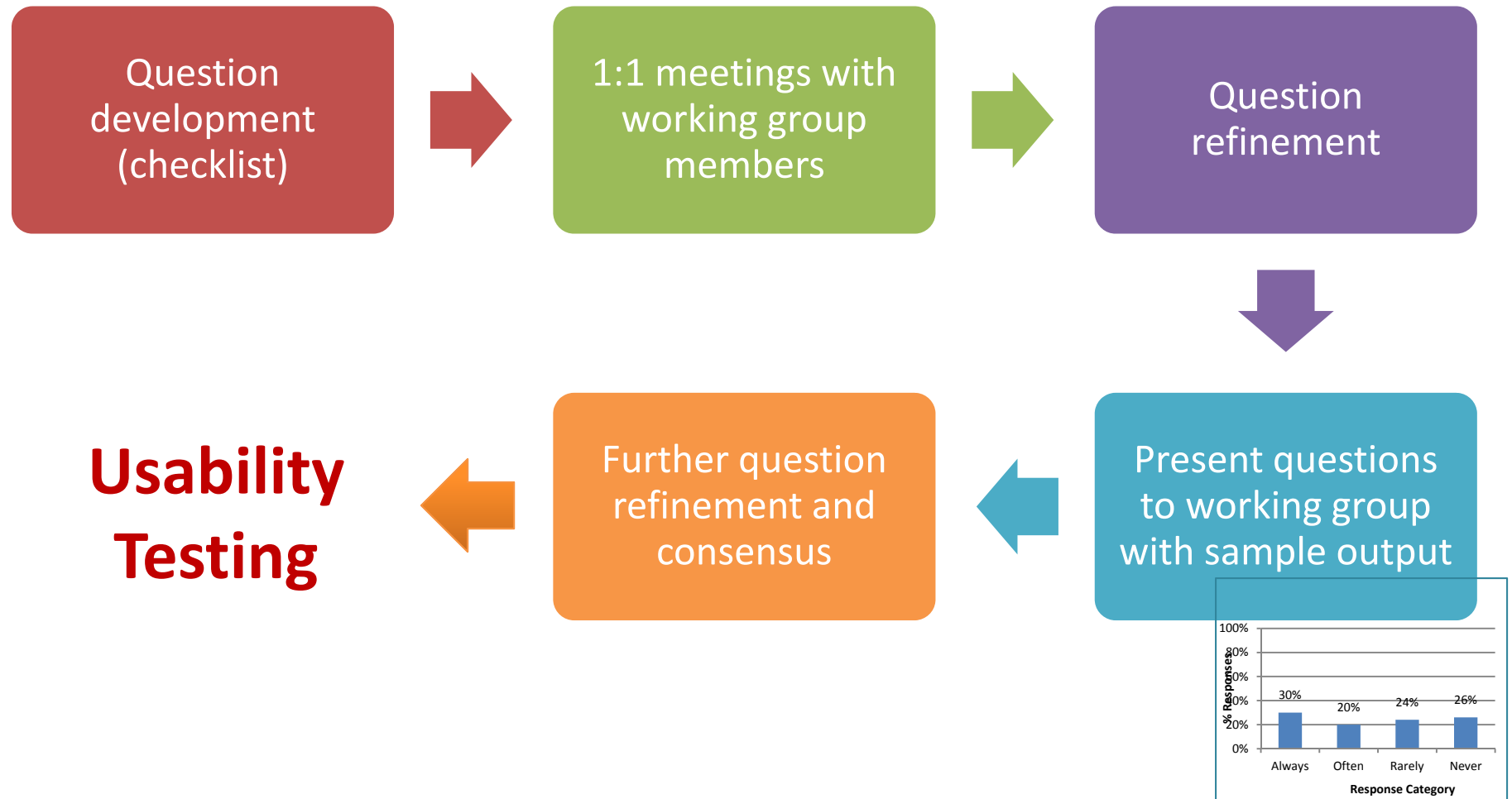
Stage 1: Domain Identification



Mapping Top 5 Domains to Average Clinic Visit



Stage 2: Question Development



Stage 3: Usability Testing (Cognitive Interviews)



Purpose



- Do questions ask what we want to know?
- Do participants understand questions in the same way?
- Are the questions easy to understand?
- Is survey easy to complete?

Process

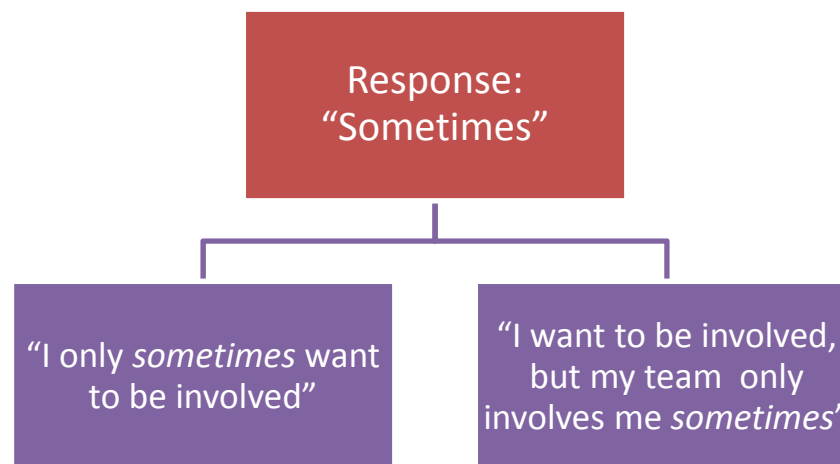


- 16 patient/family members
- Complete survey prior to interview
- 1 hour 1:1 interviews
- Real time

Interview



- "Please explain meaning of question in your own words"
- "Please walk us through the process of how you selected your response"



Step 4: Approval

- Patient and Family Advisory Council
- OCSMC
- Cancer Quality Council of Ontario



Step 5: Implementation

- Reporting template
- French translation
- Distribute to regions December 2014

Results

- Regional results returned: January 31, 2015
- Cancer System Quality Index Launch: May 20, 2015

Lessons Learned/Next Steps



- All Stakeholders involved
- Patient/Family involvement critical
- Formal review

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