Measure # 68: Patient Perceived Continuity of Care from Multiple Providers

Contact Information:
- For questions regarding this measure and for permission to use it, contact:
  Jeannie Haggerty, PhD
  Research Chair in Family and Community Medicine
  McGill University & St Mary’s Hospital Center
  3830 Lacombe Ave
  Montreal, Quebec H3T 1M5
  P: (514) 345-3511 ext 6334 F: (514) 734-2652

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PATIENT-PERCEIVED CONTINUITY OF CARE FROM MULTIPLE CLINICIANS

This appendix shows the operational definition of each subscale or element, the frame and item statement with Likert response options [optional or replaceable elements]. Formatting is discretionary, but a sample questionnaire and scoring advice is available from the authors.

Please cite the instrument as “Patient Perceived Continuity from Multiple Clinicians.”

**Relational Continuity**

*Presence of a responsible clinician:* Patient can identify one health professional (usually the family physician) who has responsibility for most of their health needs and knows the patient well.

Do you have a family doctor or general practitioner who takes care of most of your health care? (If yes, who, how long)

*Comprehensive knowledge of the patient:* The extent to which comprehensive knowledge of the patient is brought to bear in the management of the health condition by the responsible clinician.

To what extent does this person (1 = hardly at all, a little, moderately, a lot, totally = 5)

- take into account your whole medical history?
- take into account what worries you most about your health?
- take into account your responsibilities at work or home?
- take into account your personal values?

**Partnership & Confidence**

How much importance does this person give to your ideas about your care? (1 = hardly any, only a little, moderate, a lot of importance, immense importance = 5)

How comfortable do you feel discussing with this person about personal problems related to your health condition? (1 = not at all comfortable, only somewhat, moderately, very, completely = 5)

How confident are you that this person will look after you no matter what happens with your health? (1 = not very, only somewhat, moderately, very, completely = 5)

**Team relational continuity:** The extent to which a stable set of people at the regular source of care know the patient and work as a team to meet their needs.
At your clinic, other than the person who takes care of most of your health care (1 = hardly at all, somewhat, moderately, a lot, completely = 5)

- how well do you feel “known” by everyone on the care team at your clinic?
- how much can you count on everyone on the care team for help?

### Management Continuity

**Presence of one main coordinator:** Patient can identify one main coordinator (mainly family physician, also nurse, case manager, etc) who is in contact with the patient and assures all the links with the health system.

Thinking about ALL the persons you saw in ALL different places you went for your care, is there one who ensures the follow-up of your health care (doctor, nurse, other)? (If yes, who and where, is it the same as responsible clinician?)

**Extent of coordinator role:** Extent to which coordinator knows all health care needs, maintains regular contact with the patient and other clinicians, and advocates for the patient to the other clinicians.

How much does this person … (1 = hardly at all or not at all to a great deal or totally = 5)

- know about your health needs?
- seem up-to-date about health care given by others?
- help you in getting the health care you need from other clinicians?
- contact other clinicians about your health care?
- keep in contact with you even when you receive health care in other places?

### Thinking about all persons seen for care

**Clarity of roles and coordination:** The role of all clinicians is clear not only to the patient but it is obvious to the patient all the clinicians know who is doing what and when.

Were there times when persons [at your clinic] or [from your clinic and those in other places] (1 = never, almost never, sometimes, often, 5 = very often)

- told you different things (that didn’t make sense together) about your health?
- did not seem to work well together?
- did not seem to know who should be doing what in your health care?

**Evidence/Experience of a care plan:** Awareness of a care plan used by clinicians to organize the patient’s care and map of care path and health trajectory. NB: not directly observed by patient, its presence must be inferred from recall of the clinician’s actions.

Thinking about what was done, in the last X months, for your health condition. Has someone (yes, no, does not apply)

- explained to you the consequences of your condition on your health?
- explained to you why you’ll do the treatment or take the medication and how?
- explained the tests or exams that you should do to check on your health condition?
- explained about visits to other health care clinicians: why and how?
- has asked you what personal goals you would like to achieve for your health condition?
• discussed with you how you could reach your personal goals?

Information Continuity

Information gaps between clinicians: Experienced communication failures between clinicians where needed information is not available or not used at the point of care (discontinuity).

Were there times when (never, sometimes, often)
• the person you were consulting did not know your most recent medical history?
• the person you were seeing did not have access to your recent test or exam results?
• you had to repeat tests because the person you were seeing did not have access to results?
• the person you were consulting did not know about changes in your treatment that another person recommended?
• you had to repeat information that should be in your medical record?
• you had to provide the results of a specialist’s visit to the person you were seeing?

Involving patients as partners, in the information loop

Information transmitted to the patient by clinicians: Patients are included in the ‘information loop’—giving and receiving appropriate information about their health condition and treatment. Information gives them a sense of control, self-efficacy, and security to cope with new situations or complications.

Thinking about the information that was given to you by the doctors, nurses, or other health professionals, to what extent did this information (I did not need information; 1 = I was not given information, hardly at all, a little, moderately, a lot = 5)
• enable you to know what to do to stay healthy?
• enable you to know how to do your treatments at home?
• enable you to know what to do to make your health better?
• let you know how to cope with minor complications?

STAND-ALONE INDICATORS OF CONTINUITY AND DISCONTINUITY

Overall experience of planned and coordinated care: Extent to which health care functions like a well-organized machine (in the patient’s eyes).

Overall, how well organized would you say all your health care is? (1 = hardly at all, to totally = 5)
In general, do you feel that you yourself have to organize the health care you receive from different persons or different places? (response options are ordinal 1 to 5)
  □ No, the person who follows my case always does it for me.
  □ No, the person who follows my case sometimes does it for me.
  □ Yes, but it is my choice to do so.
  □ Yes, I have to organize my care more than I would like.
  □ Yes, I have to organize my care too much and it is too difficult.
INDICATORS OF DISCONTINUITY

These are indicators of problem continuity. Detailed list of reasons can be adapted to local context.

Were there times when it felt like no one in the health care system was really in charge of your health care? (3-point response: 0 = no, never; yes, at times; yes, often = 3)

Were there times during or between health care visits when you felt abandoned by the health care system or left too much to your own resources? (0 = no, never; yes, at times; yes, often = 3. If yes, indicate reasons)

Did you go to a hospital emergency room for health care? 0 = no, never, yes, at times, yes, often = 3. If yes, indicate reasons)

Were there times when your physical or emotional health suffered because your health care was poorly organized? (0 = no, never; yes, at times; yes, often = 3. If yes, indicate reasons)

Sample discontinuity reasons (Check as many as apply)
- Because I do not have a regular doctor or clinic.
- Because my regular doctor was not available.
- Because it was too difficult or too long to be seen at my regular clinic.
- Because it was too difficult or too long to be seen by a specialist or another person that I had been referred to.
- Because the person I saw didn’t really know my personal health situation.
- Because no one seemed to be in charge of my health care.
- Because the persons I saw didn’t seem to know who was in charge of my health care.
- Because the persons I saw didn’t know what others had done or told me.
- Because I didn’t know what to expect about my health condition or the next steps in my care.
- Because when things went wrong or changed, I could not get answers or advice quickly.
- Because the persons I saw gave me different information.
- Because I didn’t have the information I needed to cope with my health between appointments.