2014 Programmatic Review on Ontario Cancer Plan (OCP) IV

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Overview: 4 aspects of patients’ experiences

1. Definitions
2. Measures and their uses
3. Methods of data collection
4. Quality improvement methods
Definitions
Sound-alike terms with different meanings proliferate and appeal to different audiences

- Patient-centred, patient and family centred
- Person-centred
- Relationship-centred
- Personalised, individualised

- Patient and public involvement (PPI)
- Patient and public involvement and engagement (PPIE)
We know the dimensions of experience that matter to patients

1. Compassion, empathy and responsiveness to needs, values and expressed preferences
2. Co-ordination and integration
3. Information, communication and education
4. Physical comfort
5. Emotional support, relieving fear and anxiety
6. Involvement of family and friends

They are a mix of the ‘what’ (T) and the ‘how’ (R)

1. Compassion, empathy and responsiveness (R)
2. Co-ordination and integration (T)
3. Information, communication and education (T & R)
4. Physical comfort (T&R)
5. Emotional support, relieving fear and anxiety (R)
6. Involvement of family and friends (T&R)
Measures and their uses
We have a range of different measures

1. Patient experience and PREMS Patient Reported Experience Measures: capture data on specific aspects of treatment/care
2. Patient satisfaction: captures the patient’s evaluation of the treatment/care
3. PROMS Patient-Reported Outcome Measures: captures the patient’s perspective on whether a clinical procedure improved his/her quality of life
4. Patient-defined outcomes: captures the patient’s perspective on what matters about the treatment
### Accountability
- Users: national and regional bodies
- Frequency: annual
- Level: clinical service
- Sample: representative

### Quality Improvement
- Users: clinical teams, managers, boards
- Frequency: continuous
- Level: clinical service
- Sample: ‘our patients’

### Transparency
- Users: patients, public
- Frequency: recent, 3-6 monthly
- Level: clinical service, organisation
- Sample: locally representative
And achieve different aims/goals

1. Improve patients’ and relatives’ experiences
2. Enhance patients’ personal ability to manage/cope with conditions
3. Create the conditions for patients and communities actively to shape services
Methods of data collection
We have a range of approaches to collecting data

- Quantitative and qualitative data
- Collected at different levels:
  - National
  - Organisational
  - Service
- Patient population segmented by diagnosis, age, type of organisation, type of service
- Frequency – from annual and quarterly collections to near real time and continuous
From a variety of sources

1. Feedback from patients and relatives
   - Surveys, complaints, compliments, diaries
   - Twitter, Facebook
   - Focus groups, interviews

2. Independent observers

3. Staff
   - Surveys, observation, shadowing

4. Routine clinical and administrative data
   - Wait times, delayed discharges, readmissions, visits per week, length of visit
The UK collects data for all three purposes (accountability, QI and transparency)

1. National patient surveys
2. Family and friends test
3. National staff surveys
4. Administrative data on waits, delays, lengths of stay
5. Clinical data on outcomes
6. Complaints
7. PROMS (for some elective procedures)
Top 10 tips for measurement

1. Respect the evidence base on what matters to patients
2. Measures of transactions and relational care are relevant to patients
3. Purpose and use should dictate the type of measure
4. For all three purposes, recent data is important
5. Limit the number of data points – many surveys are too long
6. For accountability and QI, use qualitative and quantitative data
7. Tie data closely to clinical services to help clinicians identify with results
8. Clinical teams and managers need ‘near real time’ feedback about their own patients compared with others
9. The rest of the health care system should use data collected for front line services
10. Use routine data as much as possible
Improving patient experience
It is useful to distinguish between types of patient experience priority.

1. **Outcomes**
   - E.g. patients feel supported, no delays, well-informed, pain controlled

2. **Process changes to improve care**
   - E.g. create time for patients, MDT-working, policies for survivorship

3. **Structural changes to improve care**
   - E.g. mobile teams for screening
Methods tailored to aims

Outcomes: Care experiences
- Co-design with patients
- Patient and family centred-care

Outcomes: Person-centred care
- Co-creating health
- Motivational interviewing
- Patient activation

Process improvement
- Productive ward/clinic
- LEAN
Enablers for improvements in patients’ care experiences

- Clearly articulated goals
- Quality of senior leadership (managers and clinicians)
- Attitude of doctors
- Quality of team-working
- Use of systematic methods for understanding care experiences (shadowing, observation, interviews etc.)
- Ability to devise and collect relevant measures