Researcher-suggested primary care topic headings compared to patient-revised topic headings

Researcher-proposed topic headings	Patient-revised topic headings
1) More patient-centred care needed	1) Care guided by patient needs, values, preferences, and priorities
2) Communication – Informing/empowering patients	2) Informing and empowering patients
3) Improving patient-provider communication	3) Improve and strengthen communication between patients and primary health care providers
4) Electronic Medical Records (EMR)/information sharing	4) Information sharing, including electronic medical records
5) Resources to better manage one's own health	5) Resources to better manage one's own health
6) Prevention/early intervention	6) Prevention/early intervention
7) Inability to access regular family doctors (GPs)	7) Unable to find a regular family doctor or other primary health care provider

8) Inadequacy of walk-in clinics	8) Inadequacy of compensation model where doctors receive a set amount of money per visit (fee-for-service)
9) Accessing after-hours care	9) Accessing care where and when patients need it
10) Access to specialist knowledge	10) Access to specialist knowledge
11) Impact of a new diagnosis	11) Support for living with chronic conditions
12) Care of chronic conditions	
13) Accessing mental health resources	12) Mental health resources
14) Challenges in small towns/cities	13) Challenges in small towns/cities and remote areas
15) Patient stigma	14) Addressing stigma and bias
16) Gaps in clinical evidence/information	15) Knowledge gaps in clinical evidence and information
17) Broaden roles for other health care professionals	16) New models of primary care that include other health care professionals
18) Inefficient practices put pressure on the system	17) Improving continuity and coordination

19) No universal drug plan	18) No universal drug plan

Patient-revised topics and full list of bullet point examples and experiences from the interim priority setting workshop

1) Care guided by patient needs, values, preferences, and priorities

- “Block and tackle” approach to protecting territory (i.e., using defensive/offensive tactics), rather than patient-centred care
- Care needs to keep pace with patients’ expectations for information, especially in the context of widespread access to online information
- Need to embark on a journey of discovery with the patient
- Role of primary care provider is to be a coordinator of care in a team-based setting
- More holistic approach needed, where the whole body is treated, not just whatever particular part/system is ‘ill’
- Consideration of non-pharmacological options for treatment

2) Informing and empowering patients

- Information not explained to patient adequately
- Not all treatment options explained/offered, especially around alternative medicine
- Advice needs to be targeted in a way that patients know how to take action (don’t just give diagnosis)
- Information not clearly communicated to patients about how/why something being prescribed
- Treatment recommendations need to be appropriate for/tailored to the needs of the community (including low-income)
- Resources patients are directed to need to be appropriate and available based on needs of the community (including low-income)
- Guidance on red flags and when to seek care
- Strategies to address/accept ‘new normal’ after a new diagnosis
- Shock of new diagnosis may impair understanding/ability to ask questions during initial consultation
- Understanding individual patient priorities for their care and targeting care appropriately

3) Improve and strengthen communication between patients and primary health care providers

- Patients may not describe underlying issue/relevant symptoms, but questioning could identify it
- Patients may not have time/ability to process information to ask all questions during a consultation
- Enhancing decision-making shared between patients and providers
- Addressing language barriers in care
- Use recap strategy to check understanding

4) Information sharing, including electronic medical records

- Lack of coordinated information sharing between health care professionals (especially health authorities) means re-telling 'story' repeatedly & treatments/information given may never be known between health professionals and across settings including walk-in clinics, home-care, hospital
- Patients unable to access own EMR including clinical notes
- EMR often not reviewed before patient appointment, which leads to gaps in care
- Pharmanet works well in transferring prescription information between health authorities, but medical records don't similarly transfer
- Patient should not need to manage all of the communication within a care team
- Streamlined processes for patient-led consent and information sharing

5) Resources to better manage one's own health

- No access to EMR including clinical notes
- Should be ability to access information without seeing PHC physician (e.g., patient portal, patient-led chronic disease programming)
- No resources to help understand what patients can do to manage their own health (knowing schedule for check-ups, screening etc.)
- Lack of patient knowledge of clinical guidelines
- Patients need help interpreting what is and what isn't evidence-based
- Clarity needed around what to do when new to the province
- Need for centralized repositories with quality resources and programs available, including support groups

6) Prevention/early intervention

- Preventative medicine and lifestyle management not prioritized
- When, why and which health care professionals should do screening
- Lack of early interventions leads to poorer outcomes and higher cost down the road
- Roles for other professionals in preventative health care and lifestyle management

7) Unable to find a regular family doctor or other primary health care provider

- Weighing up convenience of walk-in over desire to see GP
- Places pressure on the emergency department
- Patients feel like a “product of the system”
- Hard to navigate healthcare system
- Receptionists act as gatekeepers (but without providing enough information)
- More students need to go into family practice
- Environmental/natural disasters impact patient health, which puts even further pressure on the system

8) Inadequacy of compensation model where doctors receive a set amount of money per visit (fee-for-service)

- Often not possible to discuss multiple, interrelated issues (chronic conditions)
- Encourages walk-in clinic practice which does not meet patient needs
- Walk-in clinics –line ups for appointments are for long periods (not suitable for some patients/weather) & waiting space isn’t adequate
- Need research to understand how to most effectively compensate physician

9) Accessing care where and when patients need it

- Few options for after-hours care
- Need for care in home and long-term care
- Suitability of waiting space and physical design of clinics

10) Access to specialist knowledge

- Need for rapid access to specialist care for specific questions
- Processes to get specialist information that reduce need for face-to-face access to a specialist

- Need to keep patient in-the-loop on communication between primary care and specialists
- Direct access to specialists to answer a question

11) Support for living with chronic conditions

- No support for management of a chronic disease without a family doctor
- Family GPs refusing to accept patients with ‘complex’ conditions & ethics/implications of this
- Difficult to get repeat prescriptions filled without family GP
- Limited time with physician and nurse, especially with chronic conditions
- GPs could notify patients of support programs to help cope, including peer-to-peer support
- Some conditions cause cognitive difficulties (e.g., memory problems, difficulty processing or not correctly interpreting information)
- After a course of treatment, patient left somewhat alone dealing with side effects & feeling of being on own
- Can be long intervals between appointments & patient can ‘feel lost’ in this time interval
- Patient and doctor misconceptions likely with understanding condition/treatments
- Differentiation between chronic conditions and acquired conditions and recognition that there isn’t always a causal relationship between them
- Continuity of care is essential in the context of chronic disease
- Clear communication of prognosis and pathway of care going forward, including the spectrum of possibilities

12) Mental health resources

- Often limited or no availability of resources for mental health and substance use needs
- Gap between primary care and specialists services, particularly in the absence of a diagnosis
- Information needed on how to access mental health and substance use resources
- Primary care physicians (and Emergency doctors) not qualified to manage complex mental health needs, so patients access acute care more often
- Co-existence of mental health and physical conditions poorly managed

13) Challenges in small towns/cities and remote areas

- Primary care doctors need to do more, since there are fewer specialists in small towns/cities
- Transportation needs must be considered
- Improved access to specialists also needed
- Less access to diagnostic testing
- Less choice/availability for doctors/treatments, which has larger impact on ‘complex’ conditions
- Privacy/stigma issues in rural areas (e.g., prescription pick-up)

14) Addressing stigma and bias

- Cultural safety and competency
- Community sensitivities
- Care for LGBTQ communities
- Stigma particular to transgender community
- Assumptions made based on health condition/background/socioeconomic status
- Effects of terminology, diagnoses, etc.
- Impact of stigma and bias on patient outcomes

15) Knowledge gaps in clinical evidence and information

- Issues of consistency across doctors when seeing multiple providers and levels of expertise (of GPs)
- GPs appear uncertain of correct course of care, or reluctant to perform procedures (provide clinical ‘judgement’)
- Knowledge and application of clinical guidelines
- Continuing education for practicing professionals
- Need to study who responds, not just the treatments themselves
- Treatment recommendations need to be appropriate for/tailored to the needs of the community (including low-income)
- Speed of implementation of scientific research (17 years) needs to be improved
- Patients want new treatments now, even though full evidence base may not be there
- Patients aware of differences in treatments between provinces and countries and want access to full set of options
- Scientific/research models only useful insofar as they predict outcomes in the real world – Magnitude of effect needs to be considered

16) New models of primary care including other health care professionals

- Need for better collaboration and cooperation among health care professionals and health disciplines
- Expanded roles for other health care professionals
- Better support needed for caregivers and home support workers, including respite care

17) Improving continuity and coordination

- Care outside of office (long-term care, home care) and outside of office hours is needed to ensure continuity
- Reluctance to renew prescriptions for more than three months
- Unnecessary appointments required to access services (e.g. vaccinations, physiotherapists)
- New questions occur to patients after an appointment, but no one to ask/have to make a new appointment to have these questions answered
- Emergency respondents appear well-trained, but often involves 4-6 health professionals
- Patients discharged from secondary care without ensuring adequate services in place (transportation, clean/safe home, family pressure/stress)

18) No universal drug plan

- Patients' limitations, needs & affordability/financial issues must be taken into account
    - Some 'over-the-counter' products are cheaper
    - Patients may skip/halve medications (appear non-adherent, but can't afford 'as prescribed')
    - Lack of coverage for prescription drugs puts pressure on the system elsewhere
- Difficulties with pharmacies inputting out-of-province information (when new to BC)
- Education for primary care providers on cost of prescription drugs to guide prescribing decisions