

Innovations to make Healthcare Service Better

- Improved dialogue between patient and caregiver
- Patients should have choices
- Patient care- opting to pay for healthcare
- How to hear about innovations and not re-invent the wheel
- Connecting patient innovators and collaboration
- Spreading the word of innovation in healthcare
- How to engage policy-makers and lawmakers to consider- at the early stages
- Teams should go to marginalized community such as Hastings in Vancouver
 - this avoids people going to the ER for all services
- Possibility for mobile equipment and services for better services
- Advocates should be given respect/power
- Assign an advocate to hear patients' ideas
- Being able to pay for healthcare should be an option-accountability
- We must connect patient and innovators
- Spreading the word from cities to rural areas
 - Buy in at early stages
- Patients should extend their range by creating/making their own devices, equipment etc. Rather than waiting for the industry to catch up
- Patient "Maker Fair"
- "Digital Pet" for kids at hospitals rewards are given for tests, docs, etc.
- Therapeutic dogs could help
- Food in the emergency room
- Social networking a possibility

How can Patients Collaborate?

- Form "Tetra Societies"
- Facebook- "Patient Innovators"
 - Link with those who can do it
- Connect to social Media

How to have healthcare hear about Innovations

- Read about it- "White Coat Black Arts"
- Brain/drain/dissemination to underserved communities

Adverse Event Reporting for Learning

- New Brunswick-mandatory reporting (no learning)
- Fear of a lawsuit
- Waiting upon an action for change
- Response of "internal matter"
- Fear of reporting amongst healthcare providers
- Consistent approach to event reporting

- Where do patients report
 - Patient Advocate
 - Nurse
 - Head nurse
 - Social worker
 - Clinical Supervisor
- How do Patients report?
- Debrief amongst others
- Media should bring attention to matters that are swept under the rug
- Reporting and hearing system should be present
- Europe (no fault insurance)
- Patients need to understand that adverse events occur
- Patient advocates in hospital
 - There 's a bias
- Communication between staff must improve
- Incident reports-completed by nurses are not available to patients
- No fault systems
- Patients need an advocate and be welcomed into the hospital setting
 - i.e. cot to sleep in hospital
- Patient Expert is needed
- Not all patients have the experience with the healthcare system
- Listening to patient and support system
- System changes must be made to support patient safety
- Shift in culture
- Chain of communication
- Blame free for healthcare providers?
- Systemic factors
- Complaining to college is not always the best route
- Missing element
 - Have the authority to report back to family and patients
 - Ask for recommendations to improve the system
- Frustration occurs when not knowing “who to turn to”

Participation and Power

- Power lies with the doctor
- Depending on the personality (attitude of the doctor)
- What is a participant?
- Doctor is usually the entrance into the healthcare system
- Accountability->to who?
- Consider participation in decision making
- Especially in the area of power (college of physicians)
- Grading in hospitals
- Patient's voice needs to be heard
- Participation does not equal power
- Why do doctors police doctors?

- Patients don't have power, despite participating in their care
- A separate agency should be involved with patient advocacy to manage doctors
- Make them accountable to establish balance of power
- Patients need a say in measure of accountability, and how things are done at the level of Ontario College of physicians and surgeons. If doctors were told and realized that patient voice carried weight, then it would change how things are viewed and done by doctors

How to Support Healthcare Workers So They Can Support Patients

- How do we bring hospitality into hospitals?
- In the U.S, many hospitals give guest comment cards
- Funding tied to patient satisfaction (U.S)
- Determine how patients treat staff
- Determine how leaders support staff
- How does staff support and encourage one another?
- Patients and healthcare support staff should take time to acknowledge each other
- Recognition of employees doesn't have to be big and expensive
- Have "thank you" boards or bracelet (token of appreciation)
- Announcements regarding thanks and recognition would encourage HCW
- Be mindful of cultural differences
- There is a need for caregiver support groups
- Happy staff=faster healing->doctors for patients
- Admission to any care facility requires peace and calm for patient and family
- Need to train staff to deal with situations
- Sometimes as a caregiver you have to be inventive and creative to get around the system
- Need support people for patients/families
- Communication is important-> smile and explain

Seamless Healthcare for Aging at Home

- Chronic conditions to be managed
- There is a need more hours from care providers at home
- Convert home to accommodate
 - Hospital graded linoleum
- Learn from mistakes
- Have expert O.T tour your home and make suggestions
- Convert home interiors for ease and safety of use
- Better transport or getting access to health service providers
- Hospitals should have care have graduated levels of care
- Possibility of mobile health geriatric clinics for neighbourhoods which includes health teams and social workers
- Seeing people after hours (seniors)
- Better use of nurses advanced (ACPAC) and nurse practitioners
- Observation/tracking form for service providers or caregivers regarding their health status
- Assisting families in two way communication with seniors and doctors
- Special attention and way to track seniors who have no one is needed

- Directives easily accessible to others
- Patients to provide advance care directives to their physicians for their files, care service providers to initiate this conversation
- Courses/education for families, caregivers and POA's regarding considerations for next steps as you age.
 - Seniors centres
 - Libraries
 - Community centres

Educate and Engage Patients

- Patient safety kit self advocacy (Manitoba)
- Patients should know the Bill of Rights-responsibilities
- Engagement/Mechanics
 - Patients in decision making families/caregivers
- Stop the line (SASK)
- Educate patient
 - Journey
 - Volunteers-sharing information tools
- Patient has right to speak up
- Patient navigator is needed
- Prevention and Promotion
 - How to be healthy, prepare for surgery, and treatments
- Integrated health records
 - Patient and clinician sharing info/patient maintaining a personal record
- Treat whole person as well as the disease (hospital policy)
- Educate on terminology
 - Vocabulary-> speak clearly
- Change in cultural barrier to change
 - Clinician disdain when patient asks question or volunteers info.
 - Issue of clinician self esteem

Twitter and Social Media in Healthcare

- Twitter.com-> handle is short to open account-> put in profile about yourself
- Cancer as research
- Use own name when answering , you should be authentic
- Be an active tweeter and not just about what you had for dinner
- Site->symplur-> tells you what all the hash tags are
- Follow arthritis, cancer etc.
- @hasmca-> tweet chat about a number of things
 - @ HCSMCA-> to see what is going on that week
- Hootsuite is an application this makes it easier to follow twitter
- @nursefriendly-> he's on tweet chat all the time
- Some doctors have blogs that you can follow
- Twitter restricted to 140 characters
- Short forms on twitter-> will give you an idea of what short form means

- Health depends on your social network
- @RAwarrior-> follow her
- You can block people who you don't want to follow- people that are unreliable
- Check mark on celebrities- you know have the right person not a imposture
- Patients Canada is on twitter
- Medx conference is available and you can see it
- National Institute of Health-> tweet the link
- Knowledge democracy-> Pubmed-> abstracts of paper-> research what the abstracts mean
- Look in social media for support groups
 - LinkedIn
 - Pinterest
- On the internet you find a lot of patients who know a lot, but be careful that it's the correct information that your are receiving
- Personal board-> associate with a particular board

Emergency Department and the Elderly/Marginalized General Population

- Preventive steps to keep elderly at home or LTC home
- Long wait times ER
- Volunteer support-> make patient more comfortable while waiting-> do they have special needs?
- Keep updating regarding wait times/or care
- More staff is needed in the ER
- Make people aware of the alternatives to emergency->local options are available
- 24/7 clinic in each neighbourhood or near a hospital for non emergency issues to relieve emergency stress.
- Limit number of patient members in waiting room
- Patient conditions sometimes worsen
 - Lack of Hydration, food
 - Not getting Meds
 - Exhaustion
- Family/patient access to chart to enter information
- Call ahead to ER if repeat patient
- For those living alone, a posted list of meds, contact info., medical condition also carry list of meds in purse/pocket
- In waiting room->volunteer-> hi how are you? Can I get you something
- There should be a greeter
- Staff shouldn't talk down to patient/family
- Review E.R states-> common issues-> what could be handled by well-equipped 24/7 clinic
- Is there need for more specialists?
 - Raise the cap on number of specialists trained
- Future forecasts for medical needs

Networking the Networks

- Why does the network of rare diseases have to re-learn info that other groups have discovered
- Every group or network figures out short cuts that have worked

- Is there a way for that stuff to be distributed from on network to another so that people don't all have to constantly be re-inventing the same wheel that others have not only re-invented the same wheel but have paid for with sweat, tears and life blood.

Creating Comprehensive Healthcare Teams and Defragmenting Mental Health

- How do we organize systems to work together
- How are we going to get different specialists to be less narrow minded, and open the box working with other doctors
- Barriers->
 - Narrow specialities
 - Paid for different surgery
 - Payment system needs to be changed
 - How to get OHIP into natural medical physiotherapy, massage
 - Getting medical records to combine different practices
 - Who decides what needs to be shared?
 - What is medical necessary is undefined
 - Patients need to come more accountable
- Mental health patients diagnosis don't get the same care because they are mental health patients
- Need to give patients the right tools to be more engaged
- Patient care navigators reaching out for more than services at one time
- Best Doctors Canada pulls up all your info.
 - Harvard to go through linkages
 - Goes back to your family MD-> investigation, diagnostics
- The way Doctors get paid
 - Salary makes it easier
- Differences in approaches to evidence-based medicine by alternatives health products
- EMRs designed without sufficient practical input
- Trust: across specialities
- Billing codes not representatives of actual treatments-> accountability problems
- Navigators->best doctors Canada
- Accountability with billing and how many is used and how it is perceived

Accountability

- Mission and values statements
 - How do you hold the system accountable?
 - What are you responsible for?
 - Follow up with writing
 - What is your role?
- Fear of retribution in self governed system
- Look at the mission/value system/long term care

- Transparency
 - There's fear of retribution of doctors reported
 - Patient representation at accountability level
- Legal-> limited upside
- No accountability->no process change
- Ombudsman
 - Independent voice with authority
 - Requires clear documentation
 - Patients Canada should advocate for ombudsman
 - No ombudsman in healthcare
- Doctor re-certification as well as RN
- Should be equal representation on boards doctor/patient often it's not balanced

Quality Control

- Budget issues affect quality training etc.
- Patients on boards overseeing training
- Set standards of care, sit on technical working groups\
- Electronic records->patient access and engagement
- Excel survey contingent on findings
- Must start at the bottom, give frontline workers a chance to have a say in operational issues; improve patient experience
- Key indicators to be developed for accreditation patient input
- Because it coming from the top there will be resistance from staff
 - is there a role that patient advisors could have to help providers so they know what to do
- Electronic records doesn't always work, still need to bring your own records, it's your right to see full records
- Patient controlled electronic records-> who is responsible for it? Patient or healthcare provider? Everyone. Patient empowerment
- Smaller patient load, better quality care, better quality of life for patients
- Report on certain indicators
- National patient accountability report is to see how they're doing

Privacy- Sword or Shield

- Everything can be hacked
- Barrier to "fresh start"/labelling
- Why do doctors get sued
- Who's Information is it?
- How do we empower patients
- Get doctor to understand we speak for ourselves/agents/ reps do
- Must "know" patients
- Legislation
 - Cumbersome?
 - Patchwork
- Information access across hospitals

- Educating healthcare providers about law
 - What are the rights of caregivers, family etc.
 - Should policy/law be out of concern for rare “worst case” or for probability/mass interest
 - How do we address it?
 - Law/policy makers and healthcare system, is it different for “complex” patients?
- The technology is already available to protect privacy and grant various levels of access

Issues:

- What if a person wants to start over with a new healthcare provider and all the information can be shown ?
- Believe Physicians hide behind Privacy: Physicians are concerned about being sued and may use privacy as a way not to share information as a result
- Whose information is it ?
 - Give privacy control of patient information to the patient. Patients can sign a waiver.
 - Physicians need to understand it is our information
- There is an issue of sharing information across organizations -- issue of consent
- How does a physician get to know their patient if they don't share information with the patient or with other providers ?
 - Sharing should be proactive
 - In Saskatchewan there are less privacy issues and more sharing

Observations:

- When there is more rapport between physicians and their patients, they are less likely to be sued
- There is a culture of fear in healthcare
- Legislation doesn't permit sharing or storage of data between locations and/or departments. Even in the same hospital, a patient may have more than one record and they are not shared between departments.
- Providers are not familiar with the privacy legislation
- The legislation is for the 1% of concerns and not the 99% of needs

Summary

- After we held the discussion, most felt that privacy was used as a sword against patients rather than a shield protecting patients.

SJHC: Ready (almost) to engage Patient/Families in New Ways

- Where do I go?
 - Marketing piece-> services offered->where to go
 - And what's there?
- Open discussion regarding issues
 - survey of patients (ask how)
- Knowing ED wait line
- Knowing schedule
 - Focus on person not disease
 - Follow-up and complaints
- Question all of the guests (questionnaire about follow up and what happens at home)
 - With feedback to respondents
- Med students assigned to patients
 - Follow them everywhere

- E-health records access (Sunnybrook)
- Talk, talk but never accomplish (avoid)
- Explain ways in which patient engagement could happen
 - What are the ways to contribute
- Family members participate in events
- Have skits to train staff and, patient/caregiver roles (exchange)
- Safe place to resolve issues
- Patient not an adversary
 - Empathy->put yourself in patients' position.
- Create outrage emotion workshop
- Staff support to deal with "difficult patients"
 - Staff debrief regarding "difficult patients"
- Starts at parking lot
- Attention to "bad apple" staff
 - Management training regarding counselling discipline etc.
 - Caring for the caregiver
- Communication/education
- The technology is already available to protect privacy and grant various levels of access

My Records Belong to Me

- Who is looking at my medical records
 - How long can they see it?
 - Can they print it?
 - What items can they see?
 - Who can they share it with?
 - Who has seen it?
 - What have they seen?
- Privacy legislation
 - People who think paper records are secure are mistaken
 - "I'm in the circle of care"
- Contract language
 - When you sign the contract, the fine print states that they have rights and all indemnity
- Modifying the terms can cause terrible delays in surgery sometimes
- If someone hacks into the electronic medical records, who is responsible?
- Contract language concerns-> my chart
 - There must be reasonable protections
- More people can access e-records than paper records->that's risky
- Improving privacy legislation for e-records.
- Don't let security be an obstacle
- The benefits vs harm, there are too many positives
- When you may be dying, "privacy" does not matter so much
- Keep data in public
- We need medication management and decision-making support
- If they don't understand a disorder do they look it up? Is it easier with e-records?
- Identification of drug interactions with e-records

- Configure the interaction out
- Making adverse drug reaction reporting easy
- By including it in the system the doctor cannot continue to avoid reporting
- Have the patient proof read the med notes
- Educating the patient
- Patient front page where you'd indicate what you'd want the doctor to know->including allergies, reactions, and other things that don't fit on the form
- Errors in records-> doctors need to listen to patients

College Complaints and Medical Malpractice

- Different standards used between colleges and courts
- College is supposed to be about standard of care only, not patient outcome; but they tend to pronounce on issues they have no evidence for.
- Colleges seen as unsafe, unfair by doctors
- Should be whistleblower
 - Protection for doctors
 - Also report malpractice of colleagues
 - CMPA discourage peer reporting
- Doctors streamed to incapacity stream of professional misconduct-> two streams by college
- Have college that is not run by those they are trying to police
- UK model-> other external reviewers, not just doctors
- What is done by repeat offenders of the college level
 - More than one valid complaint should trigger review
 - Ombudsman needs teeth for medical malpractice
- Patients Canada should empower ombudsman to address systemic issue in healthcare
- Civilian oversight of investigating of investigating committees
- Superficial quality control mechanisms to catch rogues are required
- We need regular way to involve patients in tracking of adverse events
 - Ask patients if they were treated with dignity-> scale? by email after doctor visit
 - There should be a process by where doctors who have been successfully sued multiple times have their license reviewed by the college
 - Law judgements should be available to the colleges
- Cautions-> should be made available to the public

Using Patients to Educate Professionals

- Patient centred committees in hospitals access to get into train
- Have a champion preferably a doctor in or with access to curriculum
- Standardized patients very different from patient partners/education
- Role for Patients Canada in educating students-> grants?->advocacy
- For need of patient voice educating students
- There is a need for a strong voice to infiltrate universities
- Patient centred care now mandated-> is that an opportunity?
- Investigate funding through SPOR strategy for patient oriented research)
- Possibility to develop research to address patient involvement in education.

Making it Mandatory

- We agree that mandatory is good how do we make it happen?
 - Lobby politicians
 - Patients Canada could put out press releases->layout the situation report the individual stories
 - Hospital admin/patient advocates need to know
 - Letters and follow up meetings
 - Doctors need healthcare professional need to champion it-> we need allies to make it mandatory
 - Both levels of government (Fed and Prov.)
- Target a province that is doing it the best
- Use then as a model
- Give press releases and credit
- How do we find a doctor or hospital that is reporting events/problems errors-> as a model
- Collect patients narratives about non-reporting of events and reactions
 - “we don’t even know how to report on this error” -> said to the patient
- Collect experience of failure to provide care and implement tests that are ordered
- How does mandatory reporting lead to more patient-centred care?
- Change actual reports to be more patient centred
- Discentive-> hospitals that report errors are punished
- Full transparency of mandatory reports
- Including public forums and online data
- Online information -availability
- Reporting of unnecessary procedures and tests
- OHIP shouldn’t pay for duplication of test
 - Unless truly necessary
 - Justification
 - When research is priorities over clinical

Final Circle Notes

Impressions of the Day

- Appreciated high level of interaction with other participants
- Appreciated having people from different backgrounds
 - Lawyers
 - Healthcare providers
 - Patients
 - Caregivers
- Number of topics were interesting
- Wondering what the conclusion is, and where to go
- Involvement-encouraging participants
- Volunteer- other participants could work on ideas together
- Opportunity to learn from each other and apply that to home situations
- How do we turn ideas into policies?
- Could participants return to own community and write letters to reps/decision makers?
- Who are the most effective people to write a letter to

- Question of advocacy
 - Concerns we cannot advocate
 - Yes we can! Through education, publishing, and research
- Concerns that actual decision making bodies should be present
- We are focused on patients becoming part of a documentary