PACER REPORTS

Understanding Safe Surgery Checklist Experiences of Surgical Patients in Alberta

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For the Surgery Strategic Clinical Network

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Executive Summary

Safe Surgery Checklist Experiences of Alberta Surgical Patients

Mary Sheridan and Sandra Zelinsky, for the Surgery Strategic Clinical Network, March 21, 2014

After Cheryl Bryk, a PACER member of the Surgery Strategic Clinical Network (SSCN) spoke of how her surgery team's use of the safe surgery checklist created a feeling of safety and inclusion, the network decided to look at the roll out of the Safe Surgery Checklist in Alberta from a patient perspective. They asked PACER the question: *How are patients involved in the Safe Surgery Checklist, what are their experiences and recommendations for improved patient experience and engagement?*

The research priorities were: provincial representation, training surgery patients as research assistants to build research capacity, and completion of project by March 31, 2104. 34 surgery experiences were investigated, from Calgary, Edmonton, High River, Lethbridge, Canmore, Stoney Plain and Fort Saskatchewan. Four research assistants were trained to conduct structured telephone and in-person interviews.

PACER research consists of three distinct phases: Set, Collect and Reflect

- ✓ In the Set focus group, patients were invited to advise on the research protocol and questions. For this study, participants were also invited and trained to take part in the creation and administration of a structured telephone interview.
- ✓ During the Collect phase, a series of 32 participants were interviewed by telephone and in person by trained patients, based on outputs from Set focus group. Interviews were recorded, transcribed and analyzed for the Reflect focus group.
- ✓ The Reflect phase confirmed the analysis resulting in further sampling of research participants to be re interviewed to introduce the actual checklist and explore how the SSC protocols might include more patient orientation and inclusion.

What patients told us

- ✓ ***Knowing is a good thing.*** There is a wide range of practice in getting ready for surgery: trolling the internet, formal information sessions (MSK), individualized sessions, meeting someone who had just had a similar surgery. Everyone interviewed felt that that preparation (when available) increased their confidence.
- ✓ ***Not just a number.*** Surgery patients experience heightened awareness and vulnerability, "I cannot save myself if these people do not do their job" (1070). They told how knowing what to expect, interactions with surgeons and medical staff, marking surgery sites, and even sharing surgery experiences increased their engagement. Waiting with family and friends

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[1] This project has been conducted as a research support function of the Patient and Community Engagement Research (PACER) program at the University of Calgary.

made patients feel less anxious and safer. They were insecure when confused about procedures and forms and when staff repeated the same question over and over. This led some to doubt that the medical staff were confident or knew what they were doing. In general, patients valued the way they were treated as noted in the following stages:

- Admission. While there is some disorganization during some large hospital admission procedures, almost all felt that they were well taken care of. One reported being told by an admission nurse, “my job is to make sure you feel safe” (1087) and another said, “volunteer guide showed us where to go” (604).
- Pre-op and holding area seem to be the weak link in the patient pre-surgery experience with a wide range of experiences being reported from feeling secure when a student nurse waited with her, to patients discovering that they had to make serious decisions without preparation.
- In the operating room (OR) patients noticed when “everyone knows what’s going on including yourself as the patient” (447); they also noticed when there was dissention in the surgery team.
- While post-op was not the remit of this study, patients insisted on contrasting the effectiveness of pre-op with their experience in post-op.

✓ ***Like going through the security at the airport.*** Patients were unaware that a checklist was being used by medical staff. Upon being told of the checklist, everyone felt that they should have been told about the process and that if they had known they would have appreciated the efforts being made to increase their safety. They then saw the checklist like the irritation of necessary checking at airport security.

Suggestions for Patient Engagement *(Refer to research report for detailed suggestions.)*

The anxiety and fear that the participants reported because of the constant questioning, checking and rechecking was associated with *the way* the checklist was applied. When informed about the checklist, they felt it would bring a sense of safety, engagement, and feeling in control, especially if patients were properly informed and recognized as part of the process.

One of the patients knew what the process could be like. She was invited to participate, shown the SSC, told that it would increase safety, and that team members would be rechecking just to make sure. Our follow up interviews suggested that the SSC be introduced prior to the surgery date. They suggested that information about next of kin contact and medications be added. They also felt a SSC should include post-operative and follow up safety.

Understanding Safe Surgery Checklist Experiences of Surgical Patients in Alberta

Introduction

Patient and Community Engagement Research (PACER) is a research training and support program hosted by the Institute of Public Health within the Faculty of Medicine at the University of Calgary. The patients who are graduates from this program have learned to carry out a unique kind of research through engaging with other patients at every step of the research process. The model for this research was developed by Marlett and Emes (2010) and engages "the specific needs, values, culture and attitudes" of patients. Patients are able to share their experiential knowledge in ways that are valuable "because it [the research] contains stories and knowledge shaped by the human values and social context" (Saunders & Girgis, 2010: 1). As an international review published by the University of Ottawa has shown, patient involvement is an effective strategy in facilitating positive changes in health planning (Pivik, 2002). As researchers patients engage with other patients in discussions which capture ideas and emerging themes directly from patient experience. This project has relied on and has been carried out by patients trained in research theory and methodologies: they collaborated in planning the process, collecting and analyzing the data and the writing of the final report.

The Patient and Community Engagement Research team was contracted in January of this year, 2014, to conduct research by patients and with patients with the intention of understanding the experiences and preferences of adult patients with the Alberta Health Services safe surgery checklist now in place across Alberta. In parallel with understanding the experiences of patients this project also helps to facilitate patient-centred care in Alberta.

We set out to explore the surgical experiences of patients from a broad perspective and then to focus specifically on the patients' experience with the checklist itself. The research question was set out in the PACER Study Protocol as: *How are patients engaged in the Safe Surgery Checklist and what are their experiences and recommendations for improved patient experience and engagement?*

This report is the primary outcome of the PACER research done between January 2 and March 21, 2014: what follows here is a description of the methods used and the findings that emerged from the data produced by the research team.

Background and Context

In 2004 World Health Organization (WHO) launched a patient safety program that called for patients to become partners in the effort to bring safety to the forefront in medical practice. In 2006 the Patients for Patient Safety group made a public statement that patient engagement was critical so that patients could become partners "to prevent all avoidable harm" (WHO, London Declaration, 2006). In 2008 the World Health Organization in collaboration with the World Alliance for Patient Safety introduced the concept of a surgical safety checklist. The checklist was to have two purposes: to ensure "consistency in patient safety" and to introduce or maintain "a culture that values achieving it" (World Health Organization, 2008, p. 21).

The language of the London Declaration was direct and strong: there has been a "perception that patients and their families are helpless or antagonistic victims" but this has "served to distance them from playing meaningful roles in the development and implementation of patient safety work in the past." The declaration pointed out that patients and their families "should be able to expect openness and honesty when things go wrong, and to be involved..." (WHO, London Declaration, 2005).

The Surgery Strategic Clinical Network (SSCN) of Alberta Health Services introduced the Safe Surgery Checklist (SSC) adapted from the WHO checklist and a user manual in February 2012 (see SSC in Appendix 1). The Surgery Quality Improvement and Safety Committee of the Surgery Clinical Network (SQISC) set up a Safe Surgery Checklist Working Group "to establish a standardized measurement infrastructure for ongoing reporting at the site and executive levels" (SSC User Manual, p.2) with a view to ensuring that the "key steps are taken on all surgical procedures" (p. 4).

The stated intention was that the Safe Surgery Checklist (See Appendix 1) would become and "integrative tool" (p.4) with a single person "to lead the checklist process" which had already proven to be successful" (p. 5). In addition to following the three part checklist, the user manual urged that the "surgeon, anaesthesiologist and nurse should review the post-operative recovery and management plan, focusing in particular on intra-operative and anaesthetic issues that might affect the patient" (User Manual, p. 12).

Methodology

The methodology for this qualitative research project was adapted from the innovative methods outlined in Grey Matters (Marlett & Emes, 2010). This methodological framework ensures that all phases of the research process involve patients as facilitators, recorders and participants from the SET Focus Group through the COLLECT phase to the REFLECT Focus Group. The following diagram illustrates the three-part design of the methodology.

Figure 1. PACER Research Methodology.

Key to understanding this unique research methodology are the ethical foundations of Patient and Community Engagement Research. The four cornerstones are Personal Integrity, Respectful Relationships, Competent and Caring Research Practices and Contributions to Health and Society (see Appendix 2). Together with the specific principles within these categories conceptualized by patients in consultation with each other we mention here two which guide us in our approach to this project. First, we seek to use of language that can be readily understood; second, we seek to share of the power of research by creating a comfortable, natural and open atmosphere conducive to sharing personal knowledge and experience. With those principles at the forefront in each phase of our research into the Safe Surgery Checklist, we openly and honestly negotiated our research activities with all participants at each stage of the project.

SET Focus Group

The initial focus group took place on January 11, 2014 at the Southport offices of Alberta Health Services and was composed of six patients with varying experiences of surgery over the past twelve months. All of these participants had experienced their surgeries at three different hospitals in Calgary. In the morning each participant together with the PACER facilitators (also patients who had experienced surgery at a Calgary hospital) were invited to share their pre-surgery experience. Over lunch the detailed flip charts were analyzed by the PACER research team and the participants. In the afternoon the PACER research team drafted a telephone interview guide based on the first analysis of the priorities as set by the Set focus group, while participants were trained in telephone interviewing. The day ended with a discussion about recruitment, supervision of participant interviews, confidential data transmission and preparations for the Reflect focus group.

The data were captured on flip charts, in detailed process notes typed on the computer, and on digital recordings that captured the verbatim conversation of participants. These three sources provided the data for designing the Collect Phase of this project. The working outline for the interviews began with an exploration of pre-surgery experience without detailed mention of the Safe Surgery Checklist. The second portion of the study focused on the checklist itself. This was done to detect if the patient was aware of the checklist without prompts.

The set focus group identified that the working outline for the interview questions should capture what matters to patients. Questions were to be set out so as to elicit information from patients about their surgical experience without imposing the view or experience of the interviewer.

Interview training was provided to those SET Focus Group patient-participants who wished to engage in interviewing other patients about their experiences of surgery. This session was designed to help patient-interviewers to understand and carry out their role in gathering data in the next phase of the project. The goal with this training was to help interviewers have a meaningful exchange about the patient's pre-surgery experience.

COLLECT Phase

An Interview Guide was designed (see Appendix 3) and provided to interviewers. Names of patients across the province of Alberta with their phone numbers were provided by Alberta Health Services, as well as through personal connections of the researchers. 32 patients were interviewed, on the phone or in person, by four interviewers – themselves also patients who had experienced surgery within the past year. Two patients were able to provide information about their experience of 2 surgeries each within the same year making 34 surgery experiences in all. 22 of these patients had surgery done in Calgary and 5 had surgery done on Edmonton. The other interviews were recorded with one patient in each of High River, Lethbridge, Canmore, Stoney Plain and Fort Saskatchewan.

Each interview was coded to preserve the anonymity of the patient.

The following table provides details about the 32 patients interviewed including where the surgery took place, when, the age range and gender of the patient.

Table 1. *Research Participants.*

Surgery	**Where**	**When**	**Age**	**Gender**
Gall bladder removal	High River	Oct. 14, 2013	40's	Female
Septum repair	Edmonton (Grey Nuns)	Nov. 24, 2013	30's	Male
Varicose veins	Canmore	Oct. 22, 2013	30's	Male
Shoulder repair	Edmonton (Grey Nuns)	Nov. 29, 2013	30's	Male
Double hernia	Stoney Plain	Sept. 10, 2013	50's	Female
Bladder repair	Calgary (Foothills)	June 27, 2013	30's	Female
Lumpectomy	Lethbridge	Dec. 18, 2013	50's	Female
Right nephrectomy	Calgary (Rockyview)	Mar. 21, 2013	50's	Female
Double mastectomy	Calgary (Peter Lougheed)	July 25, 2013	50's	Female
Surgery for varicose veins	Canmore	Oct. 22, 2013	30's	Male
Surgery on hand	Edmonton (University of Alberta)	Nov. 6, 2013	70's	Male
Tumour removal/ right hemicolectomy	Calgary (Foothills)	May 30, 2013	40's	Female
Hysterectomy	Calgary (Foothills)	July 9, 2013	40's	Female
Gall bladder	Fort Saskatchewan	Dec. 4, 2013	50's	Female
Knee Replacement	Edmonton (Royal Alexandra)	May 10, 2013	70's	Female
Screws removed from foot after fracture	Calgary (Rockyview cast clinic)	Feb. 15, 2013	40's	Female
Spinal surgery	Calgary (Foothills)	Aug.15, 2013	40's	Female

Right knee replacement	Calgary (Foothills)	Oct. 26, 2013	50's	Male
Total knee replacement	Calgary (Peter Lougheed)	Apr. 10, 2013	60's	Female
Surgery to upper jaw/palatal expansion	Calgary (Peter Lougheed)	Oct. 16, 2013	40's	Female
Ankle surgery	Calgary (Rockyview)	Jan. 1, 2013	40's	Female
Back fusion	Calgary (Foothills)	Aug. 15, 2013	50's	Female
Knee replacement	Edmonton (Royal Alexandra)	Apr. 22, 2013	70's	Female
Spleen removal	Calgary (Foothills)	Sept. 29, 2013	70's	Male
Bowel surgery	Calgary (Foothills)	July 13, 2013	40's	Female
Prolapsed bowel/pelvic wall reconstruction	Calgary (Foothills)	Nov. 26, 2013	70's	Female
Knee replacement	Calgary (Rockyview)	2012	60's	Female
Hip replacement	Calgary (Rockyview)	2013	60's	Female
Hysterectomy	Calgary (Rockyview)	July 10, 2013	40's	Female
Ureteroscopy and stent	Calgary (Rockyview)	Nov. 23, 2013	60's	Female
Hip replacement	Calgary (Rockyview)	Feb. 15, 2014	60's	Female
Pelvic wall reconstruction	Calgary (Foothills)	Nov. 27, 2013	60's	Female
Shoulder & arm repair	Calgary (Peter Lougheed)	Nov. 1 2013	70`s	Female
Malignant polyps in bowel removed	Calgary (Rockyview)	Dec. 10 2013	50`s	Female

All interviewee responses to questions were transcribed and analysed together with transcripts of the notes taken during both focus groups. Short segments of interviewee responses were numbered sequentially for accuracy and ease of reference and were clustered into categories. We call the individual responses gleaned from the within the clusters of data "bites." Including new data gathered during the Reflect Focus Group and post-Reflect Focus Group interviews, 1272 data bites have been collected for this research report.

REFLECT Focus Group

This session was held on February 22, 2014 at the Alberta Health Services Southport offices in Calgary and engaged four patients and three PACERs for approximately four hours. Data gathered from both the SET Focus Group and the Collect Phase of this project was organized into schematics to show the range and specific concerns expressed by patients about their experience of surgery. These will be described and explained in the Findings section of this report.

The agenda drawn up for this session by the co-facilitators opened with a summary of the activity of the Collect Phase: participants were given information about the numbers of interviews, age range and gender, and an overview of the locations of the surgeries across the province. The Alberta Health Services Safe Surgery Checklist was then given to the participants: the participants had never seen the list before at any time. The participants were given time to read and ask questions about the checklist and then were invited to brainstorm their initial reaction to the checklist.

Six questions were posed and participants were asked to reflect on these questions after which they were invited to share their responses. The six questions were:

1. Do you see value in this checklist?
2. What is the value in your view?
3. What might be changed?
4. What might be added?
5. When could it be used to good effect?
6. Where could it be used? i.e. at what stage of the surgical experience?

Responses to these questions emerged as new data and were captured on flip charts and in detailed process recording notes as well as in the verbatim digital recording of the session. The interview questions were presented and again participants were invited to reflect on the same questions asked of the interviewees. They were invited to also provide their responses to the effectiveness of the questions.

From the 1272 data bites gathered by the researchers an initial cluster of patient experience emerged around patient engagement in education and learning prior to surgery. This data was shown to the Reflect Focus Group participants and they were again invited to give their responses.

Two schematics were devised to present a visual overview of the findings from the data and were given to the participants (see Appendices 4 and 5). These visual overviews of the patient surgical experience focused on two central topics: patients' experience of relationships with medical staff during their surgical experience; patients’ experience of conversation with medical staff and personnel relating to their surgery.

During the last phase of the session participants were asked to suggest recommendations for the content and delivery of the Safe Surgery Checklist.

Findings

In this section we offer a description and discussion of four areas of findings that have emerged from this study. These are the shared and most common experiences and topics of concern to the patients who were engaged in surgery. These areas of concern are: 1. Patient Education and Learning Engagement prior to the Day of Surgery; 2. Patient Engagement in Relationships; 3. Patient Engagement in Conversation; and 4. Patient Engagement with the Safe Surgery Checklist. We name these four sections of our Findings as follows: 1. Knowing is a Good Thing; 2. Not Just a Number; 3. Like Going Through Security at the Airport; and 4. Knowing There's a Checklist Would be a Good Thing.

Table 2. *General Categories of Findings in Patient Engagement in the Safe Surgery Checklist.*

Categories of the Findings	Areas of Concern
1. Knowing is a Good Thing	Patient Education and Learning Engagement Prior to the Day of Surgery
2. Not Just a Number	Patient Engagement in Relationships a. Pre-op b. Holding c. Operating Room (OR) d. Post-op
3. Like Going Through Security at the Airport	Patient Engagement in Conversation a. Pre-op b. Operating Room (OR) c. Patient response to SSC
4. Knowing There's a Checklist Would be a Good Thing	Patient Engagement with the Safe Surgery Checklist

The following is a description of the general categories in the findings. The numbers in the brackets represent the numbered data "bites" to indicate the location of quotes within the data collected from multiple participants, in an anonymous way.

1. Knowing is a Good Thing

Those patients who were given learning opportunities prior to surgery had a sense of confidence about the event. Several patients told of attending teaching and learning sessions prior to their knee or hip surgeries in both Calgary and Edmonton. These sessions included written literature about procedures and a movie showing procedures (749, 832, 848-850, 1060-1063, 1124, 1143). "Hip and joint network of AHS absolutely excellent. So awesome. Preparation is just phenomenal... They have a package prepared for you and answer all questions ... They pass the information along. They follow up on things" (1124). Another patient reflected in a follow-up interview that "the more people know and understand going into surgery the better it is" (1204).

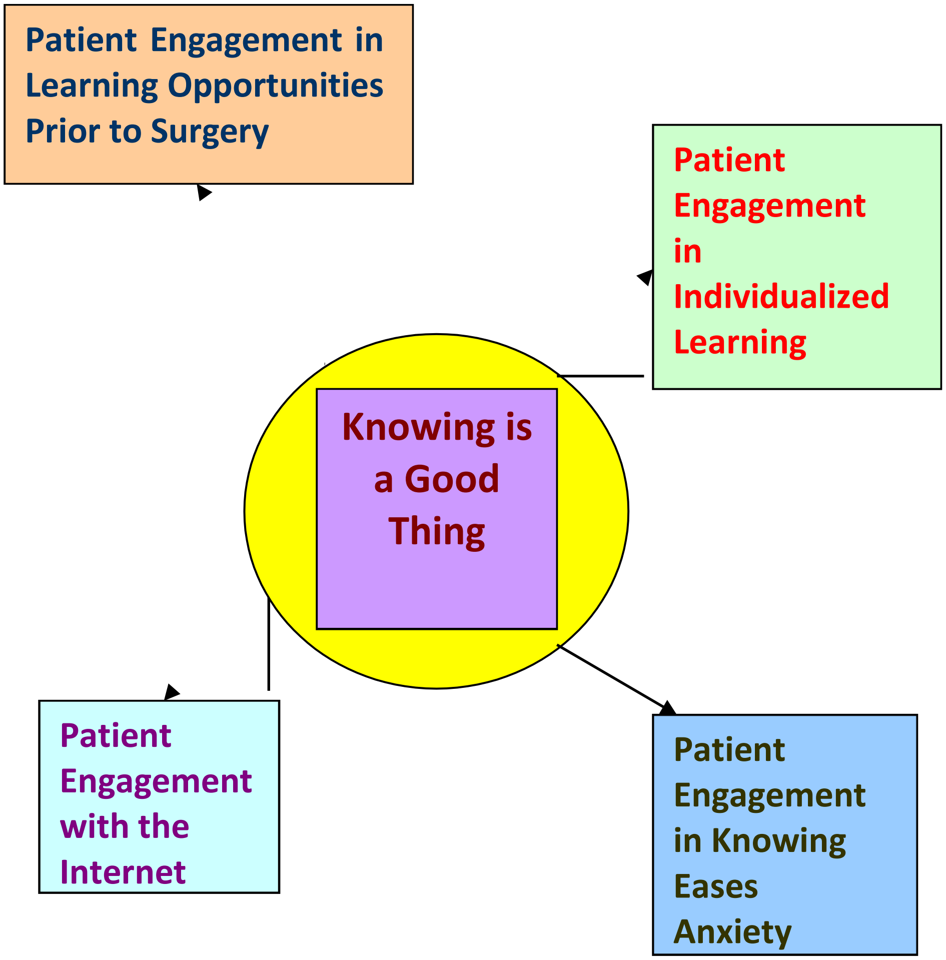

Figure 2. Knowing is a Good Thing.

Two patients told of using the Internet to search for information prior to surgery (164, 638). One patient said, "I spent hours on the computer in that short time frame from diagnosis to surgery reading my options and why some people went with a lumpectomy and why some people chose a mastectomy ... and I went on chat boards and I went on hospital sites where there were studies ... it would be nice if that information was in a pamphlet form..." (638).

One patient was provided with tailor-made preparation for her surgery. She had an interview with a nurse a week ahead of her surgery and went to a pre-assessment clinic seven days before her surgery. She felt "well-informed" and "was able to ask questions." The day before her surgery her doctor introduced her to a patient who had had the same surgery so "I knew what to expect" (863-865). This patient declared that she felt safe all along the way from diagnosis to post-op where the care was excellent (871).

Having knowledge beforehand was important to many patients because having things explained helped them to feel less anxious (21, 36, 124, 126, 261, 409, 595, 724, 729-730, 742, 1030). One patient responded that she felt more safe because she was provided with accurate clear information about how "things would go ... not even just about the procedure but first you'll go through this area and then you'll come over here..." (441).

2. Not Just a Number

Our data shows that the patient's experience of surgery is one of heightened awareness and a sense of vulnerability. As one patient put it: "the anxiety is wondering if you're going to wake up from it ... you can dispel that in a lot of ways" (655). Patients can feel very alone in these moments as they become aware of their mortality. This heightened and unpredictable emotional/psychological state can dominate the surgical experience from the moment patients are told that surgery is necessary all the way through and into the recovery period. The patient's sense of isolation is eased when engagement is "personable" and when "they talk to you by name" (25, 27). Said this same patient, "It wasn't like you were just a number" (26).

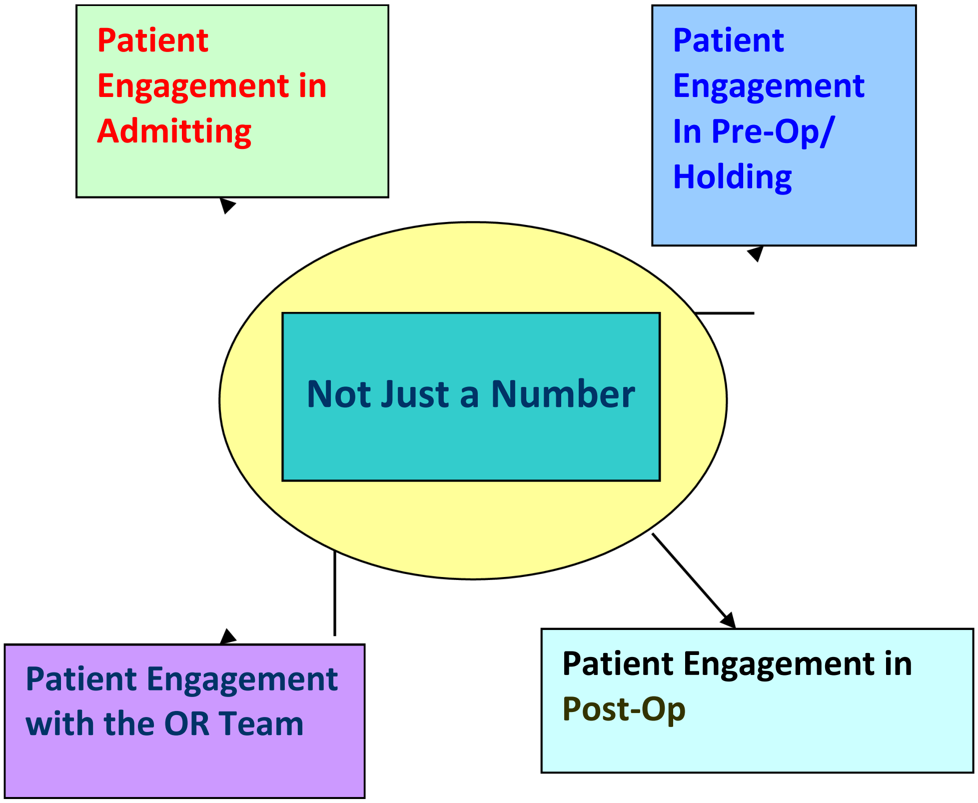

Figure 3. Not Just a Number.

One patient described her first surgery experience this way: the "anxiety was horrendous. I was going to lose control over me and my body and cannot do anything about it" (1069). This patient spoke of her fear of loss of control over her body in words which show she was very aware of being entirely dependent on practices of safe surgery. "I cannot save myself if these people do not do their job" (1070).

Admitting

The anxiety, fear, apprehension and even panic about losing control may be experienced by a patient all the way through on the journey from admitting to post-op. Direct and personal engagement with patients in an orderly and calm way becomes important at this starting point of the journey (50, 67, 149, 371, 378, 1014). One patient appreciated being told by a nurse: "My job is to make sure you feel safe" (1087). Although a few patients experienced some disorganization at admitting, many experienced an engaging staff and a smooth entry into their surgical experience. One patient said," From the time we arrived ... to the operating room everything went really smoothly" (149).

One patient spoke of her experience of panic when she arrived early in the morning to find that Intake did not open until 7 AM. There were "30 people waiting" and when the shutters opened there was a "mad dash ... I couldn't rush" (1013-1014). There was a "little piece of panic ... they opened up the offices, saw people individually, my name was the second one called" (1015). Another patient found admitting was "very disorganized" (1041). In contrast, another patient arrived to find she had a "volunteer guide to show us where to go ... I thought it was a nice touch having someone to escort you ... having all your anxiety" (604, 606).

Pre-Op/Holding

The nature of engagement by medical staff with patient can vary: being treated as a human being is highly valued at this time. One patient expressed appreciation for being talked to "by name" (27). Another patient coming for her surgery particularly appreciated having a student nurse stand with her: "It was actually quite comforting to have her there" (542).

Another patient felt very unsafe when the anaesthesiologist said: "so what have you decided to go with today? I was like whhhat are you talking about? Are you going to go with a general anaesthetic or will you be going for the epidural? I was like ah, ah, I don't know ... she said, they didn't ask you about this? I said no. She said, you were supposed to be told all about this and you were going to make a decision ... and I was like ahhh... I don't know which to do ... if it was you what would you do? She said ... well ... if it was me I'd go for the epidural but there's the risk of ... she told me the risks ... I kind of got the gist that the epidural would cover more pain so I went with that one..." (214-224).

Another patient was unprepared for her surgery because she had not been informed about bowel preparation: "... I was a little nervous about that" (195).

Operating Room (OR)

Some patients noticed whether the medical staff in OR was working well as a team or not. One patient described her experience of recognizing teamwork this way: "They all acted as though they had done this often together and I really felt like they were his team" (256). Another patient "found everyone ... seemed to work well together, like it was more of a team, no friction, everybody was friendly toward each other and the patient" (379). In contrast, another patient who had experienced more than one surgery noticed during her most recent experience that "everybody was doing their thing, but it wasn't the same ... as the first time ... the camaraderie of the team, I really noticed that" (357). One patient spoke strongly of being included as part of the team: "it's just another comfort level that ... that everybody ... is making sure that they're all doing what they're supposed to be doing ... that everyone knows what's going on including yourself as the patient" (447).

One patient told of being puzzled by the presence of student doctors and not being sure "who was doing what" and wondered if her doctor had actually done the surgery. "I don't want to be a guinea pig," she said. She had not been told that the student doctors would be present (995-998).

Post-Op

Several patients found the experience of post-op very difficult. One patient told of having a problem with her heart after surgery and being told "no one told us about your heart problem" (774). She was given conflicting directions from her doctor and the nurses: "Dr. said stay in bed, nurse said get out of bed" (779). She felt "not listened to" (780). Another patient told of feeling unsafe because three sutures did not seem enough. The doctor "didn't listen to me" (808). The "wound did not close, took longer to heal" and "bruising was excessive" (818).

A patient who had been bumped back five hours from his surgery without any explanation told of being wheeled out of the hospital by his wife: "it would have been nice to have someone wheel you down" (847). Another patient said the "only time" she felt scared "was after"; she was "not ready to get up, felt unsafe." She was taken to the gym and forced to stand up. Her sister "intervened" to prevent the patient being forced to stand (858).

Another patient had "a very good experience except for afterwards" (1009). She was unprepared to use a catheter, was not given directions and developed an e-coli infection in her bladder (1011). Another patient asked a Nurse's Aide to help her to shower and was told, "I don't have time" (1052). The patient in the next bed commented that he had not had a shower for 7 days (1053).

One patient had an undergraduate nurse take out a tube without removing the sutures (1057), and another patient had a pain crisis in the middle of the night when the pain medication was missed (1058).

One patient was never stitched up or stapled after her surgery. Steri-Strips were used and she had an allergic reaction to these developing huge blisters that scarred her stomach (269-272).

Family and Friends

The strongest sense of security and safety for patients came from having family members or friends being present with them before surgery. Four women told of feeling safe because their husbands were present (412, 533, 635, 713). One patient appreciated being allowed to have two people with her before surgery (570). Six patients were glad to have a parent or parents with them (97, 119, 141,181, 208, 285). One patient was visited by her pastor, which gave her a feeling of safety but told of the nurse being dismissive about his presence (1044-1045).

Another patient asked three times that her father living out of province be notified after her surgery was done. She was told he would be notified but this notification was not done (827-829).

Patient's Emotional/Psychological Experience

Patients may experience the journey from admitting through pre-op, the OR and post-op as an emotional and psychological roller coaster ride. One moment a patient can experience confidence, the next he or she may be overtaken by anxiety and panic. Half of the patients interviewed spoke openly about their experiences of feeling safe or unsafe often changing within the space of minutes. As one patient said, "safe surgery is not just physical but psychological ... emotional ... awareness of time is acute in this state of anxiety ..."(1166).

Patients felt comfortable when they experienced a smooth process from admitting to the OR (149, 153, 164, 442, 445, 521, 531, 813, 868).

Having knowledge and information prior to the surgery and being told what to expect helped to create a sense of comfort in patients (420-424, 453, 664, 742-745, 1060-1063, 1071, 1131). They also experienced feeling reassured when they were given knowledge about what is going to be happening to them in the immediate moments prior to surgery (372-378, 389, 484, 495, 638, 729-730, 1103).

When surgeons, anaesthetists and nurses in the OR spoke directly to patients and when there was direct engagement with the patient in making markings on the body a strong sense of trust was created (382, 438-440, 585, 615-616, 669, 724, 728, 988, 1028, 1032, 1138).

In one instance the anaesthetist shared with the patient that she too had had a lung removed the previous year. "She basically held my hand and said, 'I'm going to be with you' and she shared her experience of having had cancer one year prior" (554). This engagement with the patient created a "profound connection" which helped the patient to experience a strong sense of safety because of the shared experience (552-555).

Patients expressed feelings of instability and insecurity when they experienced confusion with staff about procedures and forms (194-196, 214- 222, 226-228, 243, 267-268, 316-317, 325, 466-469, 473, 499-500, 622-624, 836-841, 1113, 1126).

Repeated questions in pre-op and in the OR caused anxiety for some patients. Some experienced doubt that the medical staff were confident in themselves and knew what they were doing (128-130, 150-151, 174-175, 334- 336, 360, 660, 672, 868, 1028, 1035, 1136).

3. Like Going Through Security at the Airport

Our interview guide for this project was designed purposefully to engage the patient in relating his or her experience of surgery: that was the initial focus of the interview. After hearing about the patient's surgical experience and their reactions to that experience, the interviewers then introduced the Safe Surgery Checklist. All patients except one appeared to be unaware that a specific checklist was being used by medical staff either before entering the OR or in the OR. Most patients were aware, however, of being engaged in conversation about their surgery that was repetitive because the same questions were asked over and over again. They described this engagement in conversation with medical staff with the following words: "questioning", "confirming", "explaining", "reviewing", "checking" and "rechecking". One patient described her journey through surgery as "kind of like going through security at the airport" (175).

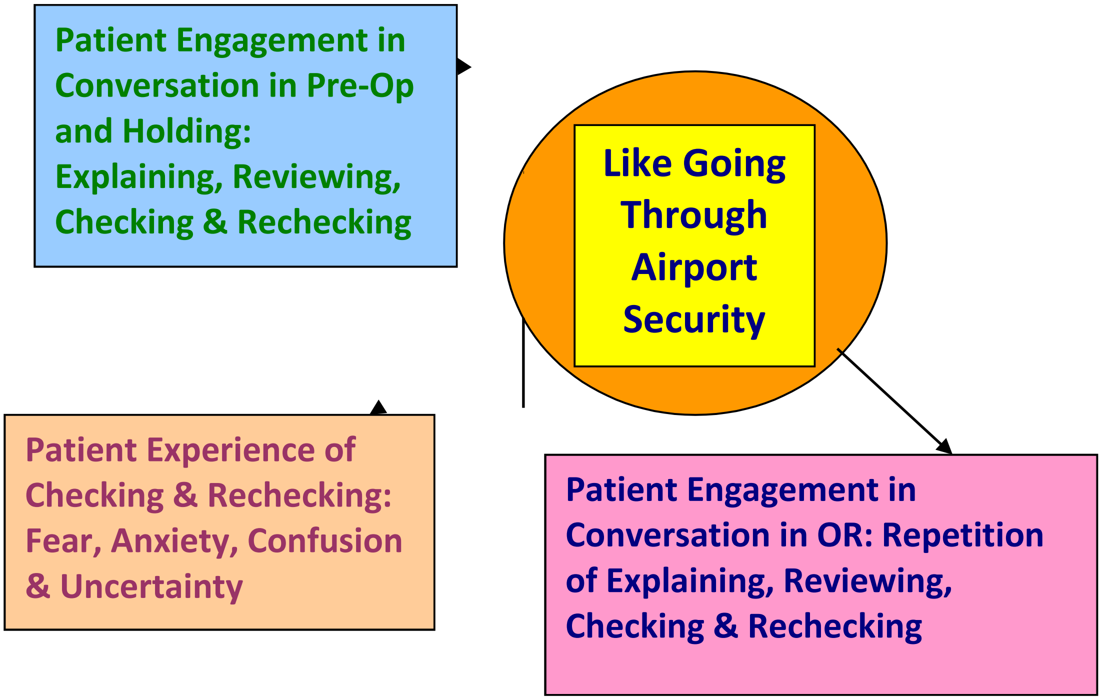

Figure 4. Like Going through Airport Security.

In Pre-Op/Holding Area

More than half of the patients interviewed spoke of being in conversation with medical staff in pre-op. The conversations included questioning the patients about their understanding of the procedures and confirming identity, explaining and reviewing the procedures, checking and rechecking the use of blood work, anaesthetics, and physical location of the surgery on the patient's body (16, 52, 55, 63-66, 132, 198, 215-224, 307, 326, 333, 375, 403, 433-437, 485, 509, 513, 660, 826, 851, 866-868, 986, 1043, 1067-1068, 1087-1089, 1127, 1136, 1139).

One patient described her experience of confirming, checking and rechecking this way: "they confirmed that [allergies] ... confirmed that I am who I am ... I betcha everyone came to talk to me confirmed that I was who I was ... asked my name a million times which is fine because at least I knew that they were making sure I was ... the person who was going to be having the particular surgery I was going to be having" (1136).

In OR

Fewer patients experienced conversation in OR but when they did, they were engaged once again in the same questions and confirmations as in pre-op. Explaining and reviewing was also done with these patients as was checking and rechecking (17-19, 24, 33-34, 92, 125-127, 133, 294, 297, 387-389, 410, 419-421, 717, 1018, 1022-1023, 1050, 1089-1090).

One patient told of his experience in OR this way: "When I was in OR she [a nurse] ... explained that there was going to be this check back and forth ... kind of cross check thing and that's exactly what happened" (421). Another patient did not recall a checklist but told of writing on his own leg: "this is the leg you're having surgery on and yes, many, many times ... Now looking back on it, it did seem they were going through a checklist ... I think it would be great for patients to know that, they're going in and all of sudden wait a minute nothing on this checklist is happening ... why not? You know at least if the patient is aware that there is some form of double checking ... to make them safe" (699-701).

Patient Response to Being Told about the Safe Surgery Checklist

Some patients told of experiencing anger and confusion with repeated questioning, experiencing fear and uncertainty about procedures (175, 289-291, 333-337, 536, 557, 566, 597, 883). A few patients commented during the interviews that they see a need for an explicit statement about the Safe Surgery Checklist (130, 293, 701-704, 449-450).

One patient described her experience this way: "I remember at one point if knowing that they do this [the checklist] would help because she was like... OK do you have any allergies ... and I was like you don't know that I'm allergic to penicillin? How many forms have I written that on ... don't you know ... you kind of get a little nervous thinking does anybody read my file? But I guess now they're actually just continually confirming everything ... so it's a good thing ... If they would have told me that way in the beginning, I would have just matter of course expected it" (333-337).

4. Knowing There's a Checklist Would be a Good Thing

One patient was told explicitly that a checklist was being used. After arriving early she was taken to be "weighed and prepped and then set up for IV" (370). Here is how she described her experience of being told about the checklist: "The lady asked if I would participate in this program ... came and talked to me ... told me what was happening and kept me informed and told me why everybody asked the same questions over ... so there would be no mistakes made in the OR" (372). Further along in the interview this patient adds, "Knowing this is why they're doing it ... that's reassuring to me because they're doing their job and that makes it a safety issue for me ... that was comforting" (389).

When told during the initial interview during the Collect Phase of this project, many patients deduced that a checklist was in use, but as one patient said, "Knowledge of that would've been a good thing" (293).

During our Reflect Focus Group we were able to gather new data about patient response to the checklist itself. One suggestion was that having the name of the next of kin would help the patient to feel more safe going into surgery (1142). Another suggestion was that medications be included on the checklist, e.g., blood thinners, vitamins. Concern was also expressed about patients having surgery who have issues with addictions.

One patient commented that the language of the checklist may be useful to staff but is not useful to the patient (1146). The checklist could be made useful to the patient if it were translated into plain language (1191).

In response to the questions posed during this session, surgery patients agreed that there is value to the checklist (1151). They also agreed that the checklist should be used at various points throughout the patient's engagement with medical staff, if possible in teaching sessions where these are available 1162), in the patient's consultation with the surgeon, at pre-assessment, in pre-op and again in the OR. One patient emphasized that there is a need for engagement throughout the process with the patient so as to establish that there is a shared concern for safety. She added that engagement with the patient and creating a sense of safety with patients will affect the recovery period in a positive way (1171).

Concern was expressed about following through with safety and the checklist into post-op. One patient commented that post-surgery orders are not always followed by staff (1159). Another patient added, "Engagement with the patient is lost if this does not happen ... resulting in delays in hospital stays." (1160). From the interview data provided it was noted that the data from two short notice surgeries appeared to reveal no mention of checking or rechecking (1163).

If the checklist is being used, the use is covert. There is a need for "clarity and purpose of the questions ... why is it being done?" (1179). Standardization of the use and delivery of the checklist is needed (1185). The use of the checklist needs to be transparent (1186) so that patients and staff alike feel safe. Concern for those patients who do not speak English as a first language was expressed by several patients (518, 1002, 1196). How can the checklist be used if the patient does not understand English? (1196). Concern was expressed also for patients with disabilities (1198).

Follow-Up Interviews After the Reflect Focus Group

Four patients were re-interviewed after the Reflect Focus Group and their responses corresponded with the responses of participants in the Reflect Focus Group. The second interview was done so that the checklist could be shown to the patients and so that the same questions posed to patient participants in the Reflect Focus Group could be asked and answered. This means that a total of seven patients have seen the checklist and engaged with the content of the checklist. The questions asked are as follows:

1. Do you see value in this checklist?
2. What is the value in your view?
3. What might be changed?
4. What might be added?
5. When could it be used to good effect?
6. Where could it be used? i.e. at what stage of the surgical experience?

Two of the four themes that emerged in the preceding Findings section re-appeared in these follow-up interviews.

1. Knowing is a Good Thing

All four patients who were interviewed a second time and saw the checklist experienced their surgeries in Calgary. All four emphasized that there would be value in knowing there is a checklist and that they preferred knowing about the checklist to not knowing (1204-1206, 1222-1223, 1257, 1268). One patient emphasized that with her short notice surgery she "didn't know anything that was happening" and was not able to see imaging displays (1228, 1234). Another patient recalled the briefing that took place as she was being prepared for surgery and the revelation that "no one had asked to go to a blood test ... people panicked ... everybody looked at each other ... then somebody asked when was your last blood test and they pulled it up on the computer so I went in surgery without that prior blood test" (1246).

Knowing before surgery means questions can be asked (1268) and that anxiety is reduced (1206,1226, 1271). One patient noted that there is a need to engage the patient with the actual existence of a checklist. The patient needs to know there is a checklist so that "you feel more involved in the expectations of what's going to happen to you" (1224). "I think I would have felt more confident in what was happening if I would have been aware of what was going on [with the checking]" (1226).

One patient suggested that the relevant tests that need to be completed be moved "to the top of the briefing or admission stage" included in the checklist (1247, 1257).

All four patients agreed that a patient version of the checklist would help to engage patients and that seeing the checklist in language that is "patient friendly" (1220) is needed at various points in the journey through surgery. One patient said the checklist needs to be shown to the patient "as early as possible" (1214) and another suggested it be shown in the doctor's office. All four said they would like to see the checklist on the day of surgery in pre-op (1215, 1232-1233, 1261, 1267).

2. Knowing There's a Checklist would be a Good Thing

Three of the four patients interviewed for a second time stated that presenting the checklist explicitly with an explanation as to its purpose and content would have been of benefit to them (1216, 1237, 1269). There was agreement that an explicit explanation and description would help to ease anxiety (1219, 1226, 1237, 1270). The one patient who did not respond to the question about making the checklist explicit was focused on remembering that when checking took place about blood tests, she learned they had not been done (1246).

Conclusion

The most important finding in our view is that while the checklist may have been in use, all but one patient had no idea why the questioning, checking and rechecking was happening. Most patients were kept in the dark during an experience that was already dark and difficult.

The data from this research project showed that there was engagement between patients and medical staff that took the form of explanations about procedures, questions about the patient, checking and rechecking: one patient was explicitly told that a checklist was being used and that its use was purposeful, that it was being used to provide a safe experience of surgery. In that one case the patient told of a sense of calm and reassurance that went with her from the moment she was told about the checklist through and into post-operative care.

When the patients being interviewed were told of the checklist in the second phase of the interview, most were able to deduce that the explanations, questioning, checking and rechecking were all related to the checklist. However, the mystification around the constant questioning, checking and rechecking often did not act as a way to helpfully engage the patient; rather, doubt, fear and anxiety were engendered.

When asked, patients responded that the safe surgery checklist is of value. The value is clear to most patients: they feel more safe with the use of a checklist than they do without one. In addition, as we see in the Findings section, patients prefer to know what is happening to them than not to know. Knowing is a good thing. The delivery of the checklist matters to patients: they do not want to be seen as just a number. They want to be engaged in their health and wellness and in honest and open conversation, which includes being informed about the checklist as to its purpose and content. Patients do not want to feel as if they are being subjected to surgery; they want to be seen as partners in the journey. Indeed, some seek out information about what is going to happen to them before their surgery. As an integrative tool the checklist can be used in ways that reinforce the patient's desire to know, ways that help the patient to call upon their own resources and resilience that will carry them through where at all possible into and through a safe recovery.

In a nutshell, the anxiety and fear that participants reported because of the constant questioning, checking and rechecking was associated with *the way* the checklist was applied. Patient anxiety occurred not because of the existence of a checklist but because they were not informed explicitly about the checklist. Not being informed can lead to mystification, which appeared to mark the experience of most patients. When told that a checklist had been used, patients recognized that there was an intention to practise safety before and during surgery. But knowing that safe surgery was a goal came after the fact, instead of before when knowing would have been most beneficial.

Patients who experienced questioning, checking and rechecking without understanding why often had a sense that staff were unsure of themselves. In several instances the dangers of surgery became heightened and anxiety also became heightened. Questioning, checking and rechecking without an explicit purpose, i.e. without having an explanation as to why the constant checking and rechecking was occurring, felt like interrogation as if the patient were some kind of security risk. This is surely the opposite of what is intended with a safe surgery checklist.

When asked, most patients could see that additions could be made to the checklist, but the major change would be in providing a kind of translation in a readable format that would educate patients about the checklist prior to surgery. Some patients could see that knowing before the day of surgery would give them time to search for and ask questions about their surgery. They could see that anxiety might be diminished and even preventable when the patient is engaged as a knowing human being rather than as a passive surgery subject.

Recommendations

The user manual that accompanies the Safe Surgery Checklist as produced by Alberta Health Services describes the checklist as an "integrative tool" (p. 4) with a single person "to lead the checklist process" (p. 5). The manual as we have quoted in the Background & Context section of this report also urges that the surgeon, anaesthesiologist and nurse "review the post-operative recovery and management plan, focusing in particular on intra-operative and anaesthetic issues that might affect the patient" (Use Manual, p. 12). These suggestions for using the checklist together with our findings lead to the following recommendations.

1. Patients should always be explicitly informed about the checklist and its purpose prior to the application of the checklist. Patients want to be engaged as partners in their surgery journey rather than be seen as surgery subjects;

2. The checklist should be made available to all patients prior to their surgery:

    a) The parts of the Safe Surgery Checklist most applicable to the patient need to be "translated" into a patient-friendly version that can be made available on the Alberta Health Care Services Safe Surgery website, or in print form, and

    b) In order to develop the checklist as an integrative tool this same patient-friendly version be given to the surgical patient as early as possible, e.g., at the Teaching Sessions for Bone & Joint surgery, or in the doctor's office;

3. One person should be designated on the day of surgery to explicitly explain the checklist and provide a description of the content to ensure the patient knows that a checklist will be used and the reasons for its use, preferably in pre-op;

4. The patient-friendly version of the checklist should be translated into other languages so that persons for whom English is a second language have access to the checklist prior to their surgery. During the application of the checklist before the surgery, an interpreter should be made available for the patient, so the patient can be meaningfully engaged in the process;

5. Persons with disabilities should have access to this patient-friendly version of the checklist in ways that accommodate the disabilities, e.g., including a family member in the explanation and description of the checklist;

6. Confirmation of recorded information about the next of kin should be included in the "Briefing" of the checklist so the surgical team does not miss the information on who to contact in emergency cases and/or after surgery;

7. The concern for patient safety and the use of the Safe Surgery Checklist should be extended into the post-operative period of time to follow the "Debriefing" phase of the checklist. Continuity is essential so that intra-operative and anaesthetic issues that might affect the patient can be included. The application of the checklist should not stop with the patient leaving the Operating Room.

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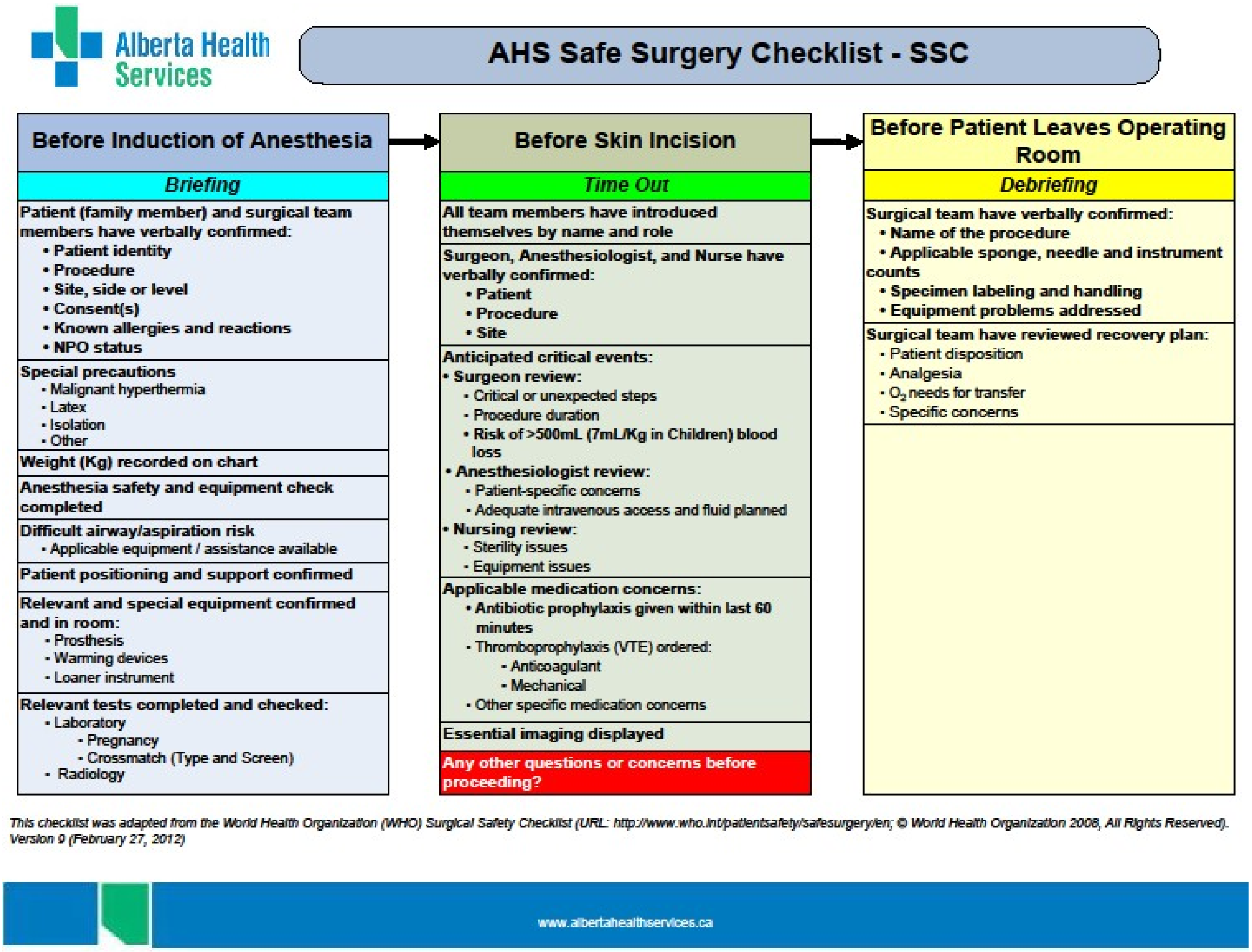
Appendix 1
Safe Surgery Checklist



Alberta Health Services

AHS Safe Surgery Checklist - SSC

Before Induction of Anesthesia

Briefing

Patient (family member) and surgical team members have verbally confirmed:
- **Patient identity**
- **Procedure**
- **Site, side or level**
- **Consent(s)**
- **Known allergies and reactions**
- **NPO status**

Special precautions
- Malignant hyperthermia
- Latex
- Isolation
- Other

Weight (Kg) recorded on chart

Anesthesia safety and equipment check completed

Difficult airway/aspiration risk
- Applicable equipment / assistance available

Patient positioning and support confirmed

Relevant and special equipment confirmed and in room:
- Prosthesis
- Warming devices
- Loaner instrument

Relevant tests completed and checked:
- Laboratory
    - Pregnancy
    - Crossmatch (Type and Screen)
- Radiology

Before Skin Incision

Time Out

All team members have introduced themselves by name and role

Surgeon, Anesthesiologist, and Nurse have verbally confirmed:
- **Patient**
- **Procedure**
- **Site**

Anticipated critical events:
- **Surgeon review:**
    - Critical or unexpected steps
    - Procedure duration
    - **Risk of >500mL (7mL/Kg in Children) blood loss**
- **Anesthesiologist review:**
    - Patient-specific concerns
    - Adequate intravenous access and fluid planned
- **Nursing review:**
    - Sterility issues
    - Equipment issues

Applicable medication concerns:
- **Antibiotic prophylaxis given within last 60 minutes**
- Thromboprophylaxis (VTE) ordered:
    - Anticoagulant
    - Mechanical
- Other specific medication concerns

Essential imaging displayed

Any other questions or concerns before proceeding?

Before Patient Leaves Operating Room

Debriefing

Surgical team have verbally confirmed:
- **Name of the procedure**
- **Applicable sponge, needle and instrument counts**
- **Specimen labeling and handling**
- **Equipment problems addressed**

Surgical team have reviewed recovery plan:
- Patient disposition
- Analgesia
- O_2 needs for transfer
- Specific concerns

This checklist was adapted from the World Health Organization (WHO) Surgical Safety Checklist (URL: http://www.who.int/patientsafety/safesurgery/en; © World Health Organization 2008, All Rights Reserved). Version 9 (February 27, 2012)

www.albertahealthservices.ca

Appendix 2: Ethical Framework of Patient and Community Engagement Research (PACER)

Personal Integrity: Acting openly with honesty and humility, ensuring that self or professional interest does not interfere with acting in the best interests of persons and peoples.

PERs will at all times endeavour to:

- Be transparent, non-judgmental, open, honest and clear in all communications.
- Disclose and negotiate agendas, roles and expectations.
- Use language that can be readily understood.
- Prevent exploitation of persons or groups for personal, professional or financial gain.
- Declare and guard against conflicts of interest.
- Be aware of the impact of power structures on people's ability to speak freely.
- Ensure that others receive credit for their work and contributions.
- Take responsibility for misunderstandings and errors in judgment.
- Know how personal and professional values, attitudes, experiences and social status influence actions, interpretations, choices and recommendations.

Respectful Relationships: Grounded in fairness and justice, is our belief in the inherent worth of all.

PERs will at all times endeavour to:

- Share the power of research.
- Seek out, welcome, appreciate and represent diversity of experience and backgrounds.
- Create a comfortable, natural and open atmosphere conducive to sharing personal knowledge and experience.
- Act to affirm that patients are experts in their lives.
- Take time to learn what patients want, need and hope for.
- Follow through with agreed upon goals and expectations.

Competent and caring research practice:
Our competence is measured by our ability to unleash the competence and capacity of patients to understand their health and health care, make decisions for themselves and to care for themselves and each other.

PERs will at all times endeavour to:

- Work together to be as competent as possible in all research we do.
- Openly negotiate research activities.
- Model engagement in our teamwork as researchers.
- Constantly evaluate and adapt methods to effectively engage all patients in research.
- Use plain language (e.g., communications, proposals, media, meetings, protocols and reports). Where technical terms are needed, meanings are negotiated, clearly defined and only used when understanding is assured.
- Maximize benefit and minimize risk, offsetting or correcting potential for harm.
- Share ownership of results to honor the contributions of all partners.
- Find ways to share findings openly and in ways that everyone can benefit.

Contributions to Health and Society: We come to this work with a commitment to health reform by actively promoting and sharing research with patients and health professionals, planners and researchers.

PERs will conduct our affairs with the highest ethical and professional standards. Our goal is to uncover insights and strategies to encourage the development of social structures and policies that benefit all persons and peoples.

PERs will at all times endeavor to:

- Produce quality research that promotes well being.
- Protect knowledge from being misused, used incompetently or rendered useless.
- Develop robust and innovative training and research methods that can be used by others.

Appendix 3
Interview Guide

Interviewer:____________________________________Date:___________________________________

Participant:_____________________________________Code:___________________________________

Age (circle): 20s 30s 40s 50 60s 70s Method (circle): face to face phone

Residing City:__________________________ Surgery Date:___________________________________

Hospital:______________________________ Type of surgery:________________________________

Interviewer Script:
Thank you for participating in this interview. I am a surgery patient who has been trained to interview other surgery patients about their experiences.

(For cold calls only): *I am working for a new program at the Faculty of Medicine at the University of Calgary, called Patient and Community Engagement Research, or PACER for short, that trains patients to become researchers. We are independent of Alberta Health Services but are working with them to provide input to the Surgery Strategic Clinical Network.*

I am a surgery patient too, I have …

This is more like a conversation, do you mind if I share ideas and ask questions while we talk? Also, before we begin, I need to get your informed consent to record this discussion. Are you ready?

A. The patient's experience:

a). What happened at the hospital on the day of your surgery?

Prompts:

- Physical space, reactions to what was happening around them
- What was happening there (chaos, privacy, public interactions)
- Interactions with the staff members and among the team, role of team members(what sets the tone, personal connections, positive or negative environment)

B. Reactions to their experience:

a). What would you like to have known ahead of time about the surgery process? (preparation, e.g., awake when going into OR, who is going to be involved, table size)

b). What added to your feeling safe or unsafe prior to surgery?

c). Were there times when you felt awkward, exposed or uncomfortable? (walking through the hall in hospital gown, privacy, being talked about)

C. Introduce Safe Surgery Checklist (what it is) and conversation:

a). How can patients benefit from knowing and understanding the checklist?

D. Interviewer reaction to the interview:

a). What did you take away from this interview?

b). Were there ideas about future research, or ideas that might improve patient engagement in the safe surgery checklist?

Appendix 4

Visual overview of the patient surgical experience: patients' experience of conversation with medical staff relating to their surgery

Appendix 5

Visual overview of the patient surgical experience: patients' experience of relationships with medical staff during their surgical experience