



Storying: The Gift that Keeps on Giving

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How did we learn about StoryCorps Legacy: Roswell Park Pastoral Care



Each one of us has a uniquely inspiring path in life that has brought us to where we are today. Every life is remarkable. It's easy to say this about others, but how often do we stop to recognize this about our own lives? Allow yourself to be heard and speak your truth! Your recording can be just for you and to share as you wish, or you may choose to share pieces of your story with the broader Roswell Park community to inspire others with your strength and resolve. This experience can be for healing yourself or for helping others, or both, and no matter what, we respect your ownership of your personal narrative.

ROSWELL PARK CANCER INSTITUTE

LIFE RECORDED

A Project Inspired by StoryCorps

We Are Roswell Park

Introduction to StoryCorps and StoryCorps Legacy

Danny and Annie



What is StoryCorps?

StoryCorps is a national oral history project whose mission is to provide people of all backgrounds and beliefs with the opportunity to record, share, and preserve the stories of our lives.



StoryCorps Legacy

StoryCorps Legacy provides people of all ages with serious illness and their families the opportunity to record, preserve, and share their stories. StoryCorps Legacy partners with organizations including hospices, palliative care providers, hospitals and disease-specific centers. StoryCorps staff train and prepare our partners to conduct and record interviews with people from their community.



StoryCorps Legacy

Who can participate in StoryCorps Legacy?

Appropriate participants are identified by our partner organizations and can be interviewed by anyone: a family member, a friend, or someone from our partner organization. At Northwestern Medicine West Region, we have chosen to focus initially on the following patient populations: hospice, oncology, Palliative Medicine and pediatrics.

StoryCorps Legacy

Where does StoryCorps record interviews?

Through StoryCorps Legacy, organizational partners are provided with portable recording equipment called StoryKits to record interviews in the patient's room, participants' homes, and healthcare facilities like the Cancer Centers.

StoryCorps Legacy

What is the StoryCorps interview model?

StoryCorps interviews are conversations between two people who know each other. In StoryCorps Legacy, participants with serious illness or their caregivers are the storytellers. They are asked open-ended questions about their lives by their partner. A staff member trained by StoryCorps Legacy is also present during the interview to handle all technical aspects of the recording and complete the necessary paperwork.

StoryCorps Legacy

What should we talk about during our interview?

People can talk about whatever they like. They are encouraged to share memories and wisdom and not worry too much about specific details, such as exact dates or locations. The StoryCorps Interview: Step-By-Step Outline, Interview Tips, and Great Questions List will help to prepare participants for the interview.

- Describe a perfect day when you were young?
- Who were your best friends growing up?
- When did you first fall in love?
- How did you get into your line of work?
- Describe the moment you saw your child for the first time?
- What are you most proud of?
- What lessons has your life taught you?

StoryCorps Legacy

How long is the interview?

The interview process takes about an hour. Recording time is 40 minutes, but can be flexible based on participant needs.

StoryCorps Legacy

What happens to recordings after the interview sessions?

StoryCorps Legacy participants receive a copy of their interview on CD to share with friends and family. With their permission, a second copy is archived for generations to come in the American Folklife Center at the Library of Congress.

StoryCorps Legacy

Is a StoryCorps Legacy interview the same as life review?

Participation in StoryCorps fosters a sense of reminiscence that may be poignant and therapeutic and one that might lead to a more formal life review, but the interview should not be mistaken for a clinical intervention or therapy.

StoryCorps Legacy

How does StoryCorps honor HIPAA and other privacy regulations?

StoryCorps is not a clinical program and does not require or maintain health records of its participants. We work through partner organizations that have existing relationships with community members and who can select participants most appropriate for this program. Participation is always voluntary, and we protect the privacy of all of our participants throughout the interview experience. If participants choose not to sign the release forms at the end of their interviews, they will receive a CD of their conversation, and StoryCorps will not keep or archive the interview with the Library of Congress.

Clarke & Beverly: *Patient Discovers Inner Artist*



Seeking and Securing Financial Resources

Alignment with organization values

StoryCorps Legacy is in alignment with:

- Northwestern Medicine's core value of Patients First ...
(*"... we remember always that caring for the individual patient and his or her family is at the heart of our mission and our philosophy"*) by eliciting the patient stories which often give rise to a celebration of lives and relationships, the things that really matter most.
- Our core value of Teamwork ...
(*"... by working together ... through the collective and coordinated efforts ... to create solutions and benefit patients."*) by coordinating patients, families, staff and volunteers to help raise up and preserve patient stories.
- Our core values of Integrity and Excellence ...
in its commitment to excellence across all aspects of the project, from collecting, sharing, and preserving stories; to organizational management; to maintaining a respectful and dignified work environment.

Seeking and Securing Financial Resources

Alignment with organization strategies

- Impact Every Day ...
(“... *about providing world class care ... that begins with listening to our patients’ stories.*”) by creating a recorded impactful legacy for families and loved ones.
- Our Magnet philosophy of Relationship Based Care ...
by enhancing three critical relationships of: the relationship between caregivers and the patients and families they serve; the caregiver’s relationship with self; the relationship among members of the health care team.
- Patient Experience and Employee Engagement ...
by strengthening connections between patients and families and staff.

Funding approval and signing of contract

- Foundation Competitive Grant Application submitted June 1, 2016
- Foundation Grant of \$16,000 awarded on August 22, 2016
- Contract submitted to organization legal department September 7, 2016
- Contract approved and signed December 1, 2016
- Facilitator Training scheduled for February 2-5, 2017

StoryCorps Legacy

Selecting and Training Team of Facilitators



1 Point Person, 3 acute care chaplains, 2 home hospice chaplains, 1 hospice volunteer manager, 1 child-life specialist, 1 volunteer

Facilitator Training

- Day 1:
 - Introduction to StoryCorps and StoryCorps Legacy
 - overview of the recording equipment
 - tips for recruiting participants
 - best practices for preparing for their interviews
- Day 2
 - focus on details of the interview process
 - hands-on practice using the StoryKit
- Days 3-4
 - Facilitators facilitate their first interviews (1-2 per day) with on-site guidance and troubleshooting from Legacy staff

Contents of StoryCorps Kit



MAIN COMPARTMENT

- 1 Archival pens
- 2 Antibacterial equipment wipes
- 3 2 Microphones with mounts and cables
- 4 Camera with battery charger
- 5 Extension cord
- 6 Recorder power cord
- 7 Recorder
- 8 Headphones



FRONT COMPARTMENT FOLDER

- 9 Signage and ID cards
- 10 Blank paperwork
- 11 Envelopes for completed paperwork

Ruthie & Gail, Mason and Alair ...
Mother, have you experienced any miracles?



Introducing project for feedback & buy-in

Presentations to:

- Department of Spiritual Care and Education
- Spiritual Journeying at Work Council
- Palliative Medicine Interdisciplinary Teams
- Patient Care Services Interdisciplinary Teams
- Hospital Leadership Team
- Cancer Center Leadership Teams
- Nurses Week recordings
- Employee Days of Spiritual Reflection recordings

Learnings & Challenges

- Importance of keeping equipment stored securely in one place
- Creation of a StoryCorps Outlook Calendar for Facilitators
- Challenge of reading handwriting in documenting demographics
- Difficulty scheduling recordings with patient short Length of Stay
- Difficulty scheduling recordings with patient changes in condition
- Difficulty scheduling Storyteller and Interviewer at the same time
- Pediatric recordings were more difficult than we imagined

Feedback from Storytellers and Interviewers

16 interviews were conducted in the first year
 30 mailings went out to Storytellers and Interviewers
 6 responded

During your recording were you the ...	Storyteller 2		Interviewer 4	
How effective was the facilitator throughout the process of explaining the program, inviting you to share your story, and arranging for the recording session?	Very Ineffective 0	Not Effective 0	Effective 1	Very Effective 5
How effective was the facilitator throughout the process of preparing the recording equipment and paperwork, the recording session, and taking your photo?	Very Ineffective 0	Not Effective 0	Effective 1	Very Effective 5
Based on your experience, if the opportunity presented itself, how likely would you recommend StoryCorps Legacy to others?	Very Unlikely 0	Not Likely 0	Likely 0	Very Likely 6

Feedback from Storytellers and Interviewers

- How many times in the past year have you listened to the recording? 3-2-1-2-2

How likely are you to listen to this recording in the future?	Very Unlikely 0	Not Likely 1	Likely 3	Very Likely 2
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- Other Comments
 - We are lucky to still have Mom (storyteller) with us – will listen more I’m sure when we lose her.
 - Thank you for recommending it. We were hesitant at first, but very glad we did it in the end.
 - The information captured during the interview was helpful in recalling moments in Mother’s life that I could include in my eulogy. Thank you.
 - Tremendous project and a worthy one!

Review of similar legacy projects

Life Review Therapy Using Autobiographical Retrieval Practice for Older Adults with Depressive Symptomatology

- Week 1: Introduction, consenting, explanation, and completed pre-test mood measures
- Week 2: completed the autobiographical memory pre-test
- Weeks 3-4-5-6: life review consisting of autobiographical retrieval practice focusing on a particular life period each week – childhood, adolescence, adulthood, etc. For each period, 14 questions were prepared designed to prompt specific memories (What is the most pleasant situation that you remember from your childhood? During adolescence, what moment do you remember as special because it was the first kiss you received or because you shared something special with someone with whom you were in love? Tell me a time you remember experiencing the most pride at work.)
- Week 7: Autobiographical memory post-test
- Week 8: Completed post-test mood measures

Serrano, JP et al

Psychology and Aging, Vol. 19, No. 2 2004

Review of similar legacy projects

Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life.

- Therapeutic sessions, running between 30 and 60 minutes, would consist of being asked to speak about things that mattered most to them, on audiotape, including things that they would want to say and be known to the people closest to them.
- Therapy sessions are transcribed and edited, and the resulting “generativity document” is returned to patients to bequeath to a friend or family member.
- Once the edited transcript was completed, another session was arranged for the therapist to read the document in its entirety to the patient. This was often emotionally evocative, because patients heard their words, thoughts, and feelings spoken aloud. Patients were invited to make any editorial suggestions, including identifying errors of omission or commission.

Chochinov HM, Hack T, et al:

Journal of Clinical Oncology, Vol. 23, No. 24, August 20, 2005.

Review of similar legacy projects

The Legacy Project Intervention to Enhance Meaningful Family Interactions: Case Studies Legacy Activities as Interventions Approaching the End of Life

- During three in-home sessions Legacy interventionists led patient-family caregiver dyads through steps of brainstorming potential projects.
- The Legacy interventionist's job was to facilitate the dyad's mutual understanding of each other's needs in their joint commitment to complete the **one** tangible Legacy (scrapbooks, photo albums, recordings, cookbooks).
- During the third Legacy intervention session the majority of time involved reviewing progress on the Legacy and evaluating the effectiveness of the intervention from the perspective of each participating member.

Allen, R

Clin Gerontol. 2009; 32(2): 164-176.

Allen, R and Hilgeman, Michelle et al

Journal of Palliative Medicine, Vol. 11, No. 7, 2008

Review of similar legacy projects

Preserving Identity and Planning for Advance Care Planning (PIPAC): preliminary outcomes from a patient centered intervention for individuals with mild dementia

- Session 1: Introduction and initiation of self-maintaining component
 - to interview the individual about important roles/domains across professional, family, leisure, and personal attributes; and determine first steps for recording their life story in a tangible way (e.g. videotape, recipe book, written letters, scrapbook, etc.)
- Session 2: Self maintaining component continued
 - to discuss progress made collecting materials for the Legacy Life Review Project between sessions
- Session 3: Self-maintaining check-in and transition to the self-adjusting component
 - to discuss continued progress, introduce ACP and complete ACP interview
- Session 4: Wrap-up and closing session
 - To review homework related to ACP, and check in regarding Legacy Project

Hilgeman, M and Allen, R et al
Aging and Mental Health, 2013

Review of similar legacy projects

Creating a duet: The Couples Life Story Approach in the United States and Japan

- 5-week intervention, the Couples Life Story Approach, helps dyads to reminisce about their life together as a couple, to work on their patterns of communication, and to develop a Life Story Book.
- Each session examines a different time period in the life of the couple starting with when they first met.
- Between sessions, the couple finds photographs and other kinds of mementoes (e.g. letters) that reflect aspects of their life story for each time period.
- These mementoes are then incorporated into the Life Story Book by the practitioner along with captions or stories that the couple provides.
- During the final session, the couple reads this book together with the practitioner and discusses ways in which they might continue to use the book over time.

Ingersoll-Dayton, B et al
Dementia, Vol. 15(4), 2014

Future Direction

Circle back to stakeholders

- Hospital Foundation
- Department of Spiritual Care and Education
- Spiritual Journeying at Work Council
- Palliative Medicine Interdisciplinary Teams
- Patient Care Services Interdisciplinary Teams
- Hospital Leadership Team
- Cancer Center Leadership Teams

Future Direction

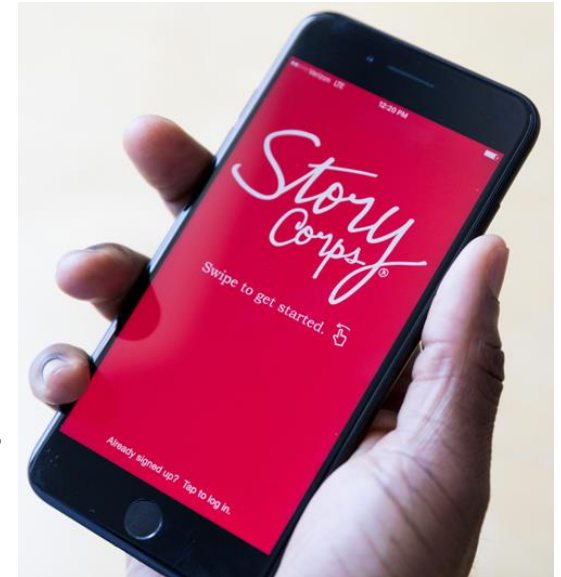
Market the program

- Cancer Centers
- Proton Center
- Hospice patient care staff
- Expand focus to outpatient services
- Drill down on pediatric services
- “Day 2” of patient care orientation, record new hire stories
- Post recordings on internal Spiritual Care website
- Continue to collect data from participants
- Name the Program

Future Direction

StoryCorps App

- **DOWNLOAD** the app from the App Store or Google Play and create a free account.
- **RECORD** a conversation with your interview partner.
- **PUBLISH** your interview to StoryCorps' online collection. It will also be preserved for future generations by the Library of Congress.
- **LISTEN** to the largest collection of human voices gathered.
- **LEARN** more at storycorps.org



Dave & Jill ... We're so blessed



Questions?

Thank You