

TEAM ALICE

Leveraging tragedy into action



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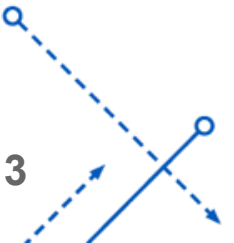
www.teamalice.org

DISCLOSURES

Nothing to disclose

Team Alice - Overview

- Origin - Alice's story
- Evolution and Mission
- Engagement strategies
 - patient / caregiver
 - provider/system
- Reflections



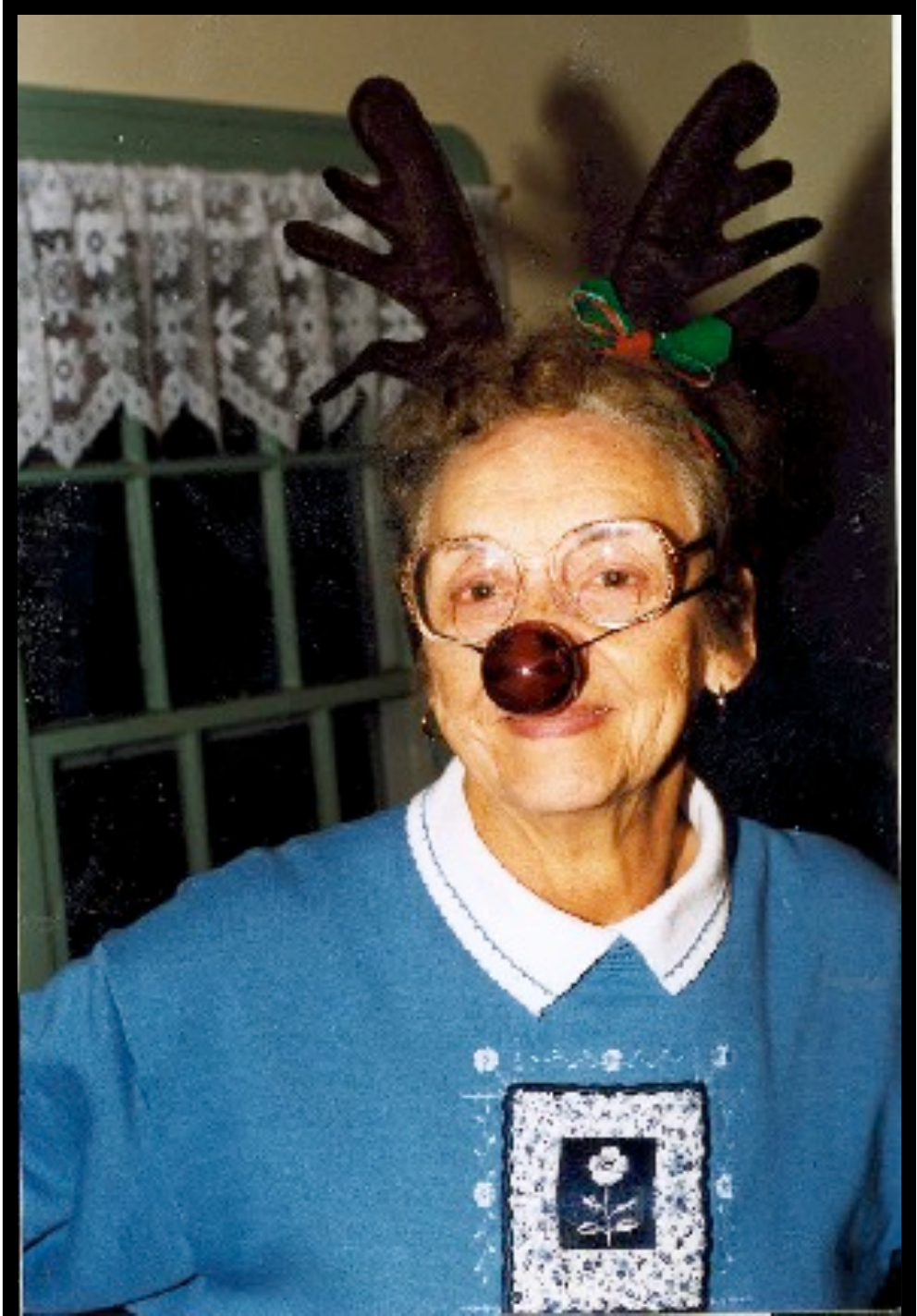
Alice's Story



Mom was engaging and unique-



***Mom loved life
and there was
never a serious
bone in her body.***



Alice's Story – “there is little more painful than losing someone to preventable medical error”.



Jul 3- Alice has neck pain and goes to the ED where she is prescribed cyclobenzaprine 10mg tid for muscle spasm. She does not take it but a few days later is told by her neurologist at a routine appt. to never take this med. She throws it away.

Jul 12- Alice has pain & swelling in right leg. Alice drives her car for the last time.

Jul 13- Alice Admitted to Hospital. Tests indicate Gout.

Jul 17- Alice Discharged to Rehab due to difficulty ambulating.

Jul 28- Mary met with staff to plan discharge to home .

Jul 29- Mary notices Alice is hallucinating. Complaints of nausea & signs of malaise.

Jul 29- Mary finds that Alice has been on cyclobenzaprine, prescribed by hospital MD and continued by Rehab MD (*known to cause severe adverse effects in geriatric patients, including psychosis*). Neither hospital or rehab pharmacy intercepted this dangerous med. Per Mary's demand, cyclobenzaprine was stopped on this date.

Jul 30- Hallucinations continue with psychosis, noted as adverse effects of cyclobenzaprine. She feels that her life is in danger and acts out. No appetite or thirst.

Aug 3- Becomes incontinent, fearful with severely altered mental state. Admitted to Hospital for severe dehydration. MRSA detected.

Aug 6- Discharged from Hospital back to rehab . Severely disoriented & falls injuring back, hand and foot. Returned to Hospital ER for x-rays and returned to rehab.

Aug 9- Unable to eat, incontinent, severe abdominal & back pain. Mary asks if she has been tested for a UTI. Psychosis escalates during evening.

Aug10- Mary told that UTI test “lit up like a Christmas tree” indicating serious UTI. Alice taken by ambulance to hospital. Alice weighs 132 lbs..

Aug11- Alice again severely dehydrated & now has MRSA & UTI. Paranoia and psychosis continues.



Aug13- Mary told Alice's medical issue was psychiatric & she should be discharged to Psych facility. Anti-psychotic med prescribed, Haldol (*serious side effects including confusion, loss of appetite, difficulty walking and speaking, tremors, all of which Alice experienced while on the drug*). Mary refuses transfer & requests emergency consult with UB Chief of Geriatrics.

Aug18- UB Geriatrician determines that she is not delusional. He recommends removal of all adverse meds. In his opinion, damage done by medication cascade is likely irreparable due to her emaciated state.

Aug19- Mary told by hospital that Alice's white blood count is alarmingly high. Advised to sign a DNR. Alice is now suffering from C-Diff & Apnea begins.

Aug20 Alice is 108 lbs. (down 24 lbs.. in 10 days). Unable to eat or drink for days. Mary requests Hospice evaluation. Denied by Hospital MD.

Aug21 Mary again requests Hospice assessment. Denied again. Mary takes request to admin & is granted. Hospice staff determine she is near death.

Aug22- Discharged from hospital to Hospice House..

Aug24- Upon arrival at Hospice, Alice had MRSA, UTI, C-Diff, & VRE (an often fatal infection).

Aug29- Alice dies of Sepsis at Hospice -6 weeks after it all began.

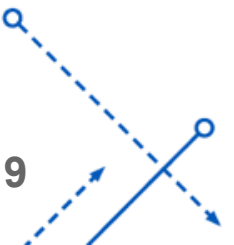
Aug 22-

- When Alice was discharged from the hospital and taken to Hospice House, 5 weeks after the cascade of events began.
- 1 week before her death.
- This is the face of ***Medication Harm!***



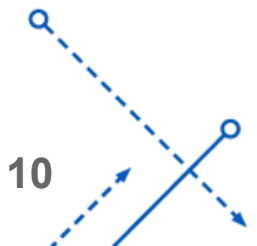
Genesis and Evolution of Team Alice

- August 29, 2009- Alice Brennan dies horrific death from avoidable medication cascade.
- Fall 2011- Mary begins telling the Alice Story at the national level. Today's webinar is the 15th time she has told her mother's story to a national audience.
- Spring 2011 to June 2020 – Alice Story presented 96 times to over 2,800 interprofessional students (Mary and Ranjit have done 64 lectures to over 1,000 medical students using the Alice Story).
- July 27, 2015- Alice Story published online by JAMA Internal Medicine
 - Brennan-Taylor MK. "Mom, you have to trust me". *JAMA Internal Medicine*. 2015;175(9): 1441-1441.



Genesis and Evolution of Team Alice

- June 2016 – Ranjit and Bob meet to begin moving Alice Story interprofessional education into research inspired by Alice- group became known as “**Team Alice**”
- Fall 2016 to June 2020 – Team Alice attracted many interprofessional faculty, NRSA post docs, and students from- Family Medicine, Pharmacy, Geriatrics, Nursing, Social Science, Epidemiology, and Human Factors Engineering. (Team roster on website)
 - Trainees successes
- Spring of 2017 - **Team Alice Deprescribing Partnership of Western New York** was established including over 25 community stakeholders across the health system.
- Spring of 2018 - **Team Alice Elder Voices** was established including patients and caregivers that advise and develop patient-driven deprescribing tools.
- Raison d'être – **How to save people like Alice.**



Mission statement

To protect seniors from medication-related harm across the continuum of care by a three-pronged approach.

1. To conduct & disseminate interdisciplinary **research** aimed at **protecting seniors from harm due to medications, across the continuum of care.**

2. Interprofessional **education** (IPE)

To equip current and future healthcare team members with the skills needed to work collaboratively across settings to prevent medication-related harm across the continuum of care.

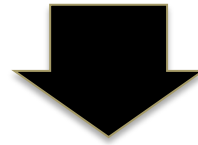
3. **Advocacy** for policy and system change nationally

To advocate for policy and system change by sharing Alice's story and our research findings with relevant government (state and national), regulatory, health plans, and other organizations across the system.

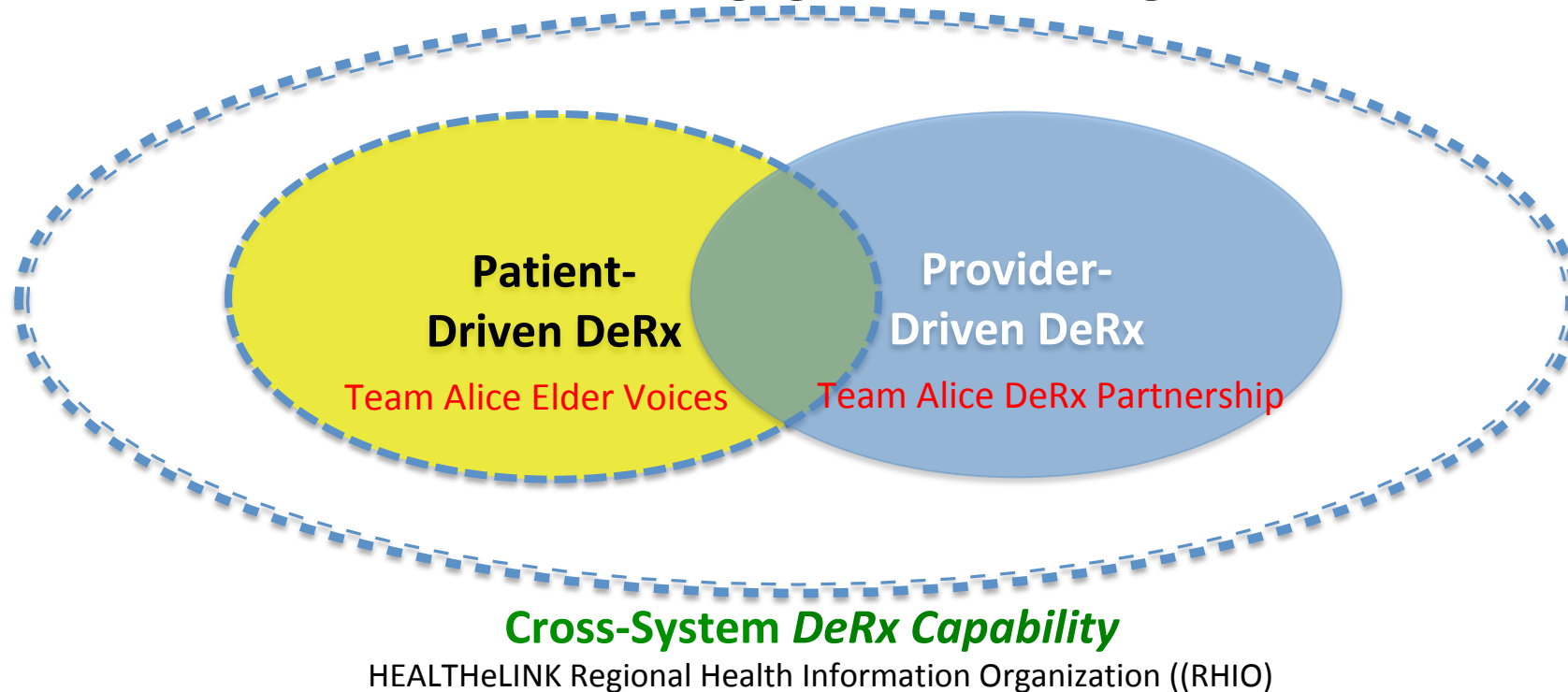
• We aim to leverage these three synergistic approaches to make a lasting difference

Stakeholder Engagement

TEAM ALICE Mission:
Research, Education and Advocacy

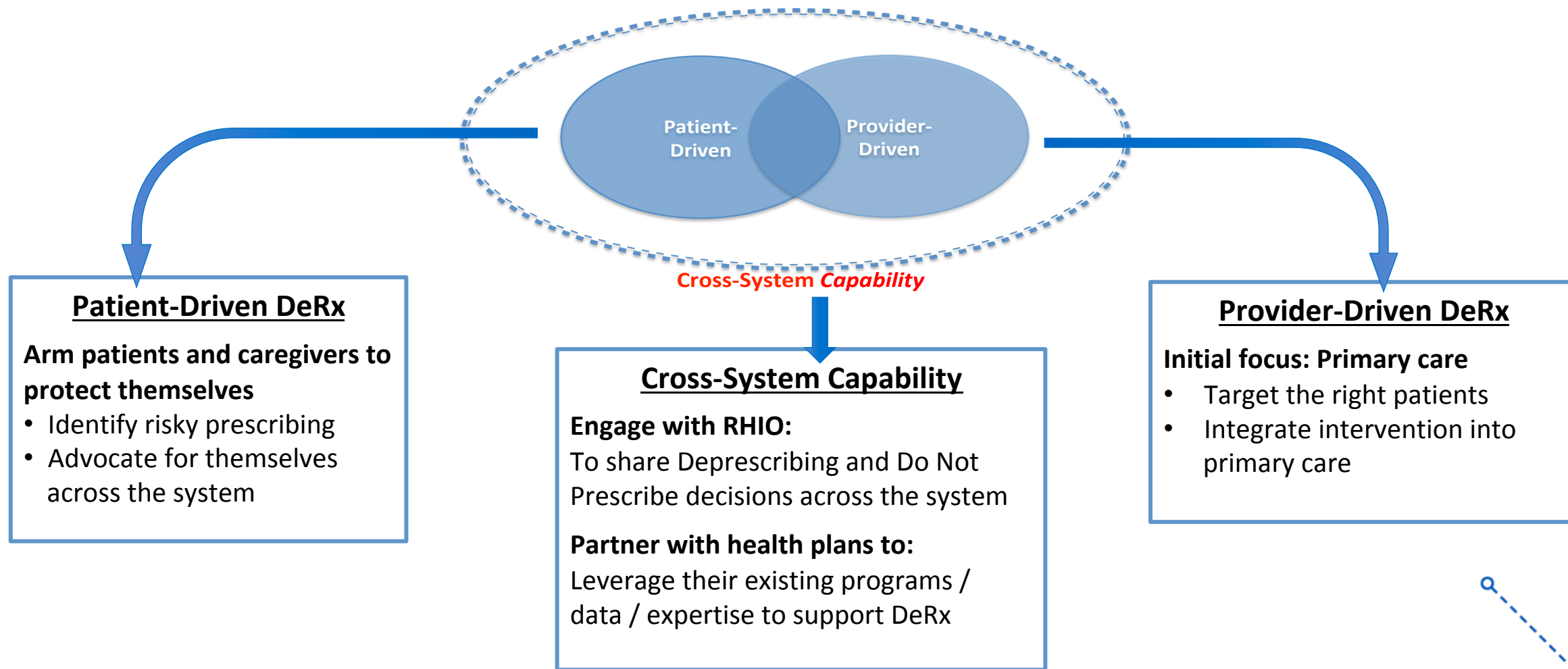


Stakeholder Engagement Strategies



TEAM ALICE

Overall Strategic Plan



Patient-Driven DeRx

Current Project:

Development of video animations to encourage patient-driven deprescribing

- Funding: RRF Foundation for Aging
- Aim: Develop and test educational videos for patients and caregivers on safe prescribing and deprescribing
- Driving Question: What would have saved Alice?

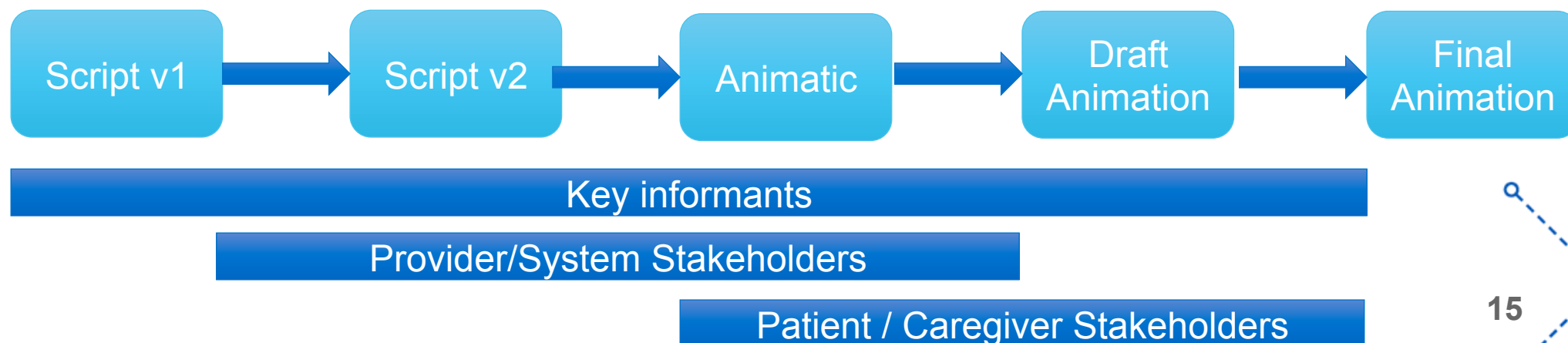


Patient-Driven DeRx

Development of video animations to encourage patient-driven deprescribing (contd.)

Overall Approach:

- CBPR-inspired, in consultation with local group (Patient Voices Network)
- Kick-off by key informants
- Cycles of input and revision by multiple stakeholder groups over 9 months



Patient-Driven DeRx

Development of video animations to encourage patient-driven deprescribing (contd.)

Key informants (Alice's family):

- Roles:

- What would have saved Alice?

“What do you wish you had known then that you know now that would have saved Alice?”

- Draft scripts in Alice's voice summarizing key lessons under three themes
- Final arbiters of feedback from other stakeholders

Patient-Driven DeRx

Development of video animations to encourage patient-driven deprescribing (contd.)

Provider/System Stakeholders (DeRx Partnership)

- **Roles:** Feedback on scripts, animatics
- **Members:** DeRx partnership, LTC Ombudsmen

Patients and Caregiver Stakeholders (Elder Voices)

- **Long Range Goal:** Expand Team Alice Elder Voices (to drive multiple future projects)
- **Roles:** Feedback on animatics and video drafts
- **Recruitment: 3 Senior Centers**
 - Leveraged existing groups – AARP Aging Mastery Program



Patient-Driven DeRx

Development of video animations to encourage patient-driven deprescribing (contd.)

Prelim Results

1. Senior Centers: 2 Rounds: 45 and 39 participants respectively across 3 centers
-Round 1: mean age 69, 92% female, 65% African American
2. Examples of input that was incorporated
3. Example of video draft after one round of revisions): <https://vimeo.com/390379993>

Next steps: Finalize and test the videos in various settings

Deprescribing Partnership of Western New York

- Why do we need it?
 - Alice's story – Failure to sustain DeRx
 - Pilot work and literature – patient, provider and system barriers.
- What is it?
 - Advisory collaborative on our mission of education, research and advocacy
 - Health care providers, patient advocates, academics, others
 - Representing – Primary care, long-term care, home-health care, health plans, RHIO, local foundations.

Deprescribing Partnership of Western New York

- Partnering to:
 - Identify measures and outcomes of importance
 - Design pragmatic study of deprescribing
 - Sites to carry out both investigation and implementation.
 - Learning from each other about the interoperability of partners in regard to DeRx.



Example of Provider Driven interdisciplinary DeRx research.

- DeRx Partnership collaboration: Pilot project on DeRx interventions
 - Medical group contribution
 - Innovative video capture of patient/provider interaction
 - Behavioral aspects of healthcare decision making
 - Incorporating Social work
 - Team Alice contribution
 - Application of human factors and cognitive work analysis
 - Incorporating Engineering



Alice- *Embracing Life- circa age 25*

Mary's thoughts on how her family's tragedy has been able to help others

Q/A