

# ADVANCE CARE PLANNING IN HOMELESS HEALTHCARE

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National Health Care for the Homeless Conference & Policy Symposium



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# Presenter Disclosures

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

# 1. Background

Should we discuss advance care  
planning in persons experiencing  
homelessness?

# What is Advance Care Planning?

- Health Care Proxy(HCP)/Surrogate
- Code status
- Living will/Advanced Directive (AD)
  - MOLST/POLST
- Organ Donation
- Burial vs. cremation

**Health Care Proxy**

(1) I, \_\_\_\_\_  
hereby appoint \_\_\_\_\_  
*(name, home address and telephone number)*

\_\_\_\_\_

\_\_\_\_\_

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) **Optional: Alternate Agent**  
If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint \_\_\_\_\_  
*(name, home address and telephone number)*

\_\_\_\_\_

\_\_\_\_\_

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. *(Optional: If you want this proxy to expire, state the date or conditions here.)* This proxy shall expire *(specify date or conditions)*: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

(4) **Optional:** I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. *(If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.)* I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions *(attach additional pages as necessary)*: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

In order for your agent to make health care decisions for you about artificial nutrition and hydration *(nourishment and water provided by feeding tube and intravenous line)*, your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

# 4 Pathways for Surrogate Decision Making

- **Directed decision making-** specify decisions in advance in writing, such as a living will
- **Delegated decision making-** specify a healthcare power of attorney
- **Devolved decision making-** if no one is specified, family members by default become healthcare proxy
- **Displaced decision making-** court-appointed guardianship or surrogate

# BARRIERS TO DISCUSSION:

- There are more immediate & pressing problems
- I don't have time; patients experiencing homelessness are too complicated
- Patients experiencing homelessness don't want to discuss advance care plans
  - Too depressing, they are estranged from family or friends
- Due to mental illness, patients experiencing homelessness cannot understand or discuss advance care plans
- Documents will not make it to the hospital; this is not an effective use of clinical time

# 1. There are more immediate and pressing problems

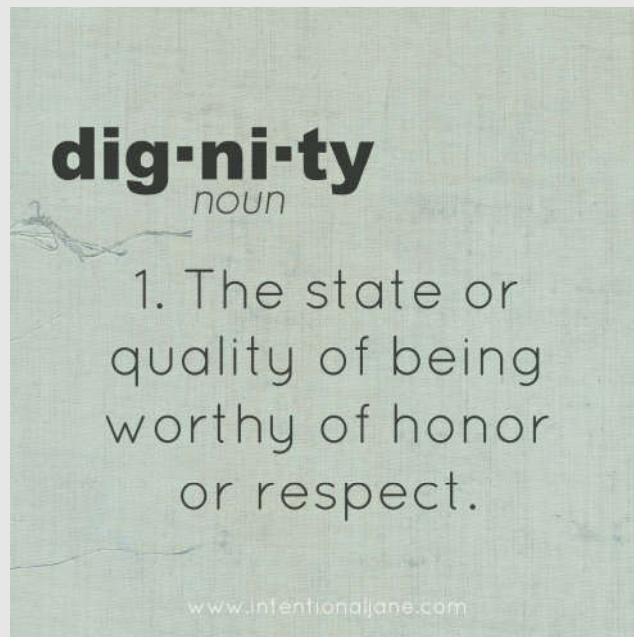
- The population of elderly persons experiencing homelessness is growing faster than the general US population
- Adults age 50 and above experiencing homelessness are sicker than their peers, have more difficulty with ADLs & IADLs, and have higher morbidity and mortality



Sermons and Henry, 2010; Brown, et al 2013; Nagourney 2016; Leung 2015



## 2. I don't have time; patients experiencing homelessness are too complicated



- Homeless adults rarely have the opportunity to discuss and document advance care plans
  - 2% of homeless men in Canada had completed an AD prior to one study
- Persons experiencing homelessness have unique needs and perspectives compared to housed patients
- They worry that they will have lose control over maintaining their dignity and end of life preferences in their future care

Tarzian 2005, Norris 2005, Song 2007, Song 2008, Song 2011, Leung 2015

### 3. Patients experiencing homelessness don't want to discuss advance care plans

- All studies in this limited research area should that persons experiencing homelessness are able and want to discuss advanced care plans

The screenshot shows the top portion of a journal article page. At the top is a dark green header with the journal title "Palliative Medicine" in white. Below the header is a light grey navigation bar with five buttons: "Home", "Browse", "Submit Paper", "About", and "Subscribe". To the left of the main content area, there is a vertical sidebar with the text "J Gen Intern Med", "Published online", "Engaging", "John Song, M", and "Nancy Ulvesta". The main content area features the article title "Chronically homeless persons' participation in an advance directive intervention: A cohort study" in bold black text. Below the title, the authors are listed: "Alexander K Leung , Dhruv Nayyar , Manisha Sachdeva , John Song , Stephen W Hwang". To the right of the authors is the text "D, 1,3". Below the authors, there is a line of smaller text: "Petroskas, BSN; Melissa West, MD; Anne Marie Weber-Main, PhD; Leah Grengs; Lillian Gelberg, MD, MSPH". At the bottom of the article preview, there is a link: "Article, Author, and Disclosure Information". In the top right corner of the page, the identifier "C2596520" is visible.

## 4. Due to mental illness, patients experiencing homelessness cannot discuss advance care plans

- Norris 2005: compared end of life wishes for 229 homeless patients vs 236 physicians vs 111 oxygen-dependent COPD patients in Seattle-cross-sectional survey
- Song 2010: 263 homeless patients in Minnesota- RCT
- Leung 2015: 205 homeless Canadian men in an alcohol harm reduction program- cohort study

\*All prospective research studies not performed as part of routine care



## 5. Documents will not make it to the hospital; this is not an effective use of clinical time

- Gruzden et al: In adults 65+ presenting to the ED, over 50% have a named health care proxy and over 40% had a living will, but only 4% of the study population have this documented in the hospital electronic health record
- Leung et al 2017: patients who completed an advance directive in a shelter-based study were more likely to have use of an advance care directive documented while hospitalized than those who did not complete an advance directive



Gruzden 2016, Leung 2017

# The Case of LR

- 85 yo Spanish-speaking male with Alzheimer's dementia without a health care proxy
- Formerly homeless, lives in supportive housing program
- New onset asymptomatic, dark diarrhea 3-4x daily, unintentional weight loss x 3-4 weeks
- Barium enema: mass concerning for rectosigmoid neoplasm



Case report slides adapted from "Consent, Dementia, and Surrogate Decision-making: Ethical Challenges in the Context of Homeless Health Care"- roundtable presentation with Mark Fox, MD, PhD, MPH at the National Health Care for the Homeless Conference & Policy Symposium 6/2016

Should we discuss advance care  
planning in persons experiencing  
homelessness?

**YES!**

# Questions in Advanced Care Planning in Persons Experiencing Homelessness


- What is the size of the population who lacks a health care proxy?
- How can we reduce the size of this population?
- What are the end of life wishes of adults experiencing homelessness?
- How do you ensure that documents make it to the hospital?


HEALTH CARE PROXY  
*for*

---

NAME

*distributed by*

 Healthcare Association  
of New York State



FOR MORE INFORMATION, contact the patient representative at your local hospital.



# 2. Methods

# CQI Project

- From 4/1/2016-6/6/2017, we sought to discuss and complete HCPs and other advance care directives for IFH homeless patients during primary care visits and focused visits with an RN in an APN/MPH program
- Copies of directives were:
  - Provided to patients
  - Scanned to the EHR
  - Stored at the transitional homeless sites
- In addition, wallet sized HCP cards were given to patients

**HEALTH CARE PROXY**

I, \_\_\_\_\_, of \_\_\_\_\_

STREET \_\_\_\_\_ CITY \_\_\_\_\_ STATE \_\_\_\_\_

DAYTIME PHONE \_\_\_\_\_ EVENING PHONE \_\_\_\_\_

hereby appoint \_\_\_\_\_, of \_\_\_\_\_

STREET \_\_\_\_\_ CITY \_\_\_\_\_ STATE \_\_\_\_\_

DAYTIME PHONE \_\_\_\_\_ EVENING PHONE \_\_\_\_\_

*as my health care agent to make all health care decisions for me if I become unable to decide for myself and, if my agent knows my wishes, decisions about artificial nutrition and hydration. This proxy will remain in effect indefinitely, unless I revoke it or state an expiration date or expiration circumstances (see special instructions).*

**OPTIONAL: Organ and/or Tissue Donation**  
I hereby make an anatomical gift, to be effective upon my death, of (check any that apply):

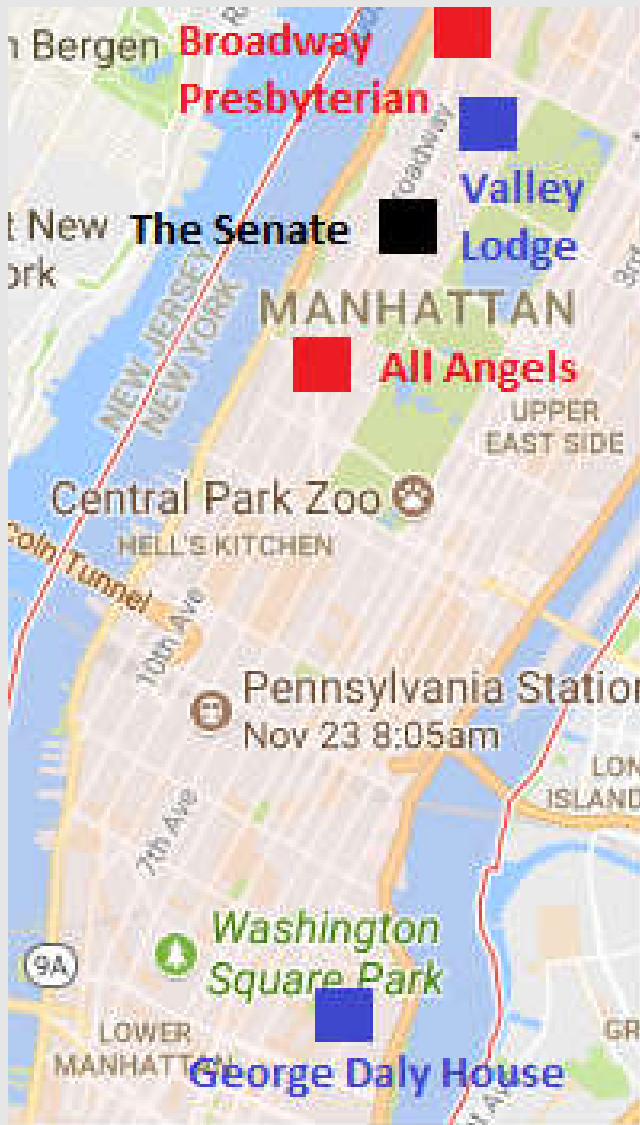
Any needed organs and/or tissues

The following organs and/or tissues \_\_\_\_\_

Limitations \_\_\_\_\_

*If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.*

SIGNATURE (PROXY INITIATOR) \_\_\_\_\_ DATE \_\_\_\_\_



# IFH ADULT HOMELESS PROGRAM

## ■ Drop-in Centers

- All Angels Church
- Broadway Presbyterian Church

## ■ Transitional homeless shelters

- George Daly House
- Valley Lodge

## ■ SRO

- The Senate

# Documenting Health Care Proxy Status

Does the patient have capacity to appoint a surrogate decision maker?

NO

YES

Has a health care proxy been signed previously?

Does the patient have a surrogate to appoint?

NO

YES

NO

YES

Unbefriended/  
Adult Orphans/  
Unrepresented/  
Isolated

Surrogate if  
patient lacks  
capacity

“Surrogateless”

Sign Health Care  
Proxy

# Retrospective Chart Review

- In the summer of 2017, we conducted a retrospective chart review of documented advance care plans and documents scanned to the EHR
- Inclusion criteria: All patients of the IFH homeless sites who:
  - a) has their PCP at one of the homeless sites
  - b) saw their PCP at least twice during the study period
  - c) aged 40 years or above

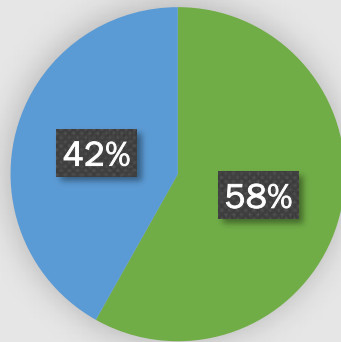


# 3. Results

# Advance care directives discussed

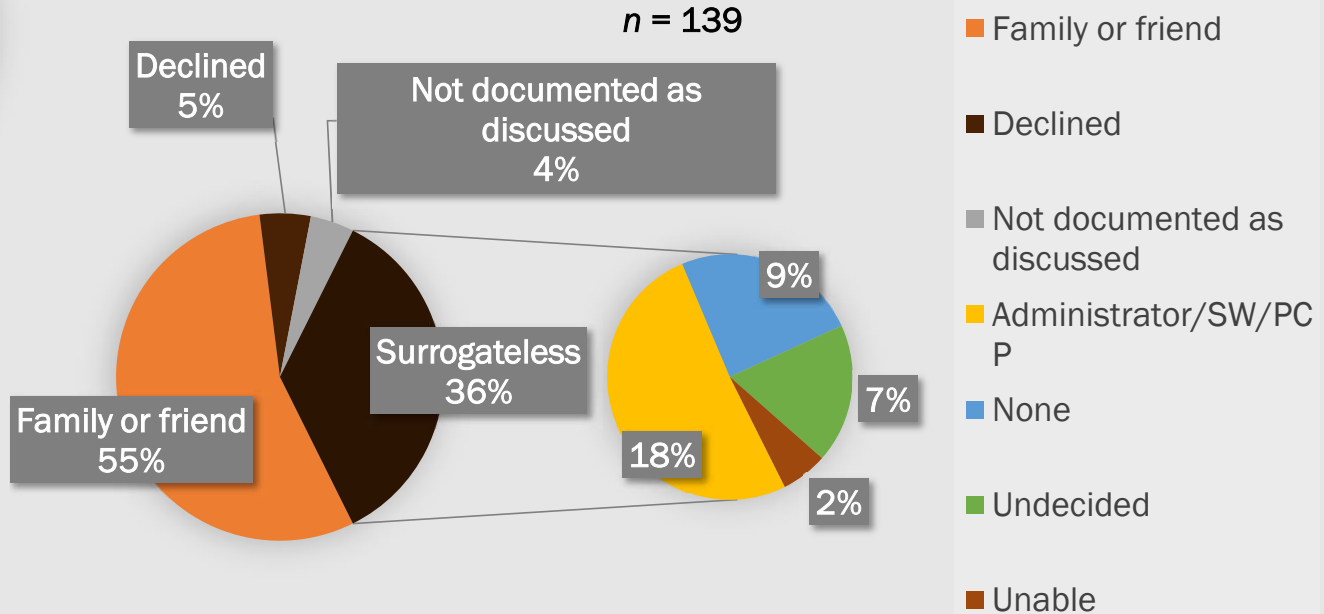
n = 332

- Not discussed
- Discussed



# Health care proxy status

n = 139



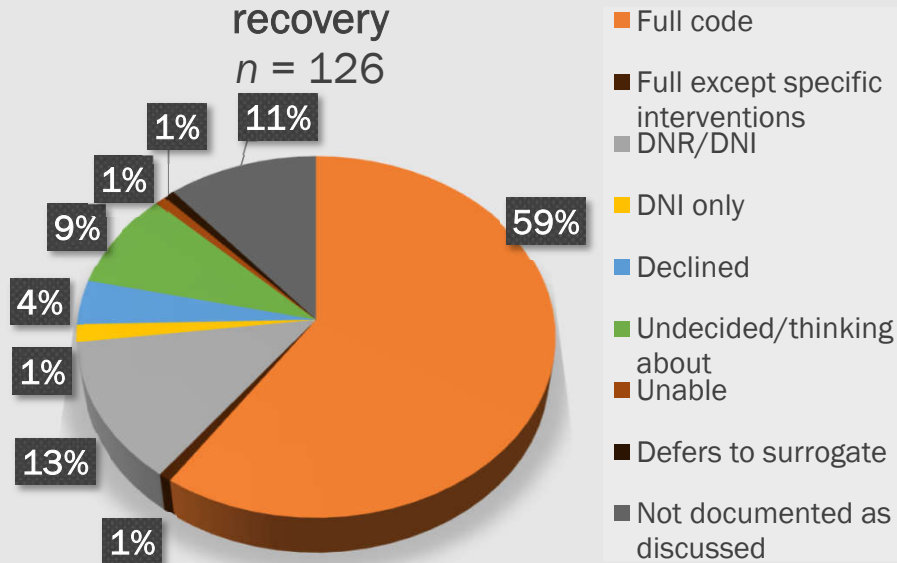
Demographics	Family or friend		Surrogateless		p-value
	<i>n</i> = 77		<i>n</i> = 49		
<b>Age</b>	<i>n</i>		<i>n</i>		
<b>Over 70 years</b>	14	18%	13	27%	0.27
<b>Under 70 years</b>	63	82%	36	73%	
<b>Mean (sd)</b>	64.8 (7.8)		65.8 (8.4)		0.53
<b>Sex</b>	<i>n</i>		<i>n</i>		
<b>Female</b>	28	36%	19	39%	0.79
<b>Male</b>	49	64%	30	61%	
<b>Race and Ethnicity</b>	<i>n</i>		<i>n</i>		
<b>Black Non-Hispanic</b>	29	38%	19	39%	0.44
<b>Other Non-Hispanic</b>	5	6%	1	2%	
<b>White Non-Hispanic</b>	19	25%	16	33%	
<b>Hispanic/Latino</b>	18	23%	12	24%	
<b>Unknown</b>	6	8%	1	2%	
<b>History of Mental Illness</b>	<i>n</i>		<i>n</i>		
<b>Yes</b>	32	42%	25	51%	0.30
<b>No</b>	45	58%	24	49%	
<b>History of Dementia</b>	<i>n</i>		<i>n</i>		
<b>Yes</b>	6	8%	6	12%	0.41
<b>No</b>	71	92%	43	88%	



*Pearson Chi-Square for categorical; t-test for continuous measures		Family or friend		Surrogateless		p-value
		n = 77		n = 49		
<b>History of Substance Abuse</b>		n		n		
	<b>Yes</b>	22	29%	12	24%	0.62
	<b>No</b>	55	71%	37	76%	
<b>3 or more medical co-morbidities</b>		n		n		
	<b>Yes</b>	40	52%	20	41%	0.22
	<b>No</b>	37	48%	29	59%	
<b>End-stage diagnosis</b>		n		n		
	<b>Yes</b>	2	3%	1	2%	0.84
	<b>No</b>	75	97%	48	98%	
<b>Died by end of study period</b>		n		n		
	<b>Yes</b>	5	6%	1	2%	0.25
	<b>No</b>	72	94%	48	98%	
<b>Visits with Primary Care Provider</b>						
	<b>Mean (sd)</b>	11.8 (8.2)		12.7 (9.4)		0.60
	<b>Median</b>	10		10		
<b>Visits with Social worker/Case worker</b>		n = 9*		n = 15*		
	<b>Mean (sd)</b>	5.2 (4.9)		8.6 (16.5)		0.57
	<b>Median</b>	4		3		
		<i>*not provided by IFH at all sites</i>				
<b>Time in primary care of homeless sites (months)</b>						
	<b>Mean (sd)</b>	49.8 (55.4)		67.1 (61.4)		0.10
	<b>Median</b>	28		41		

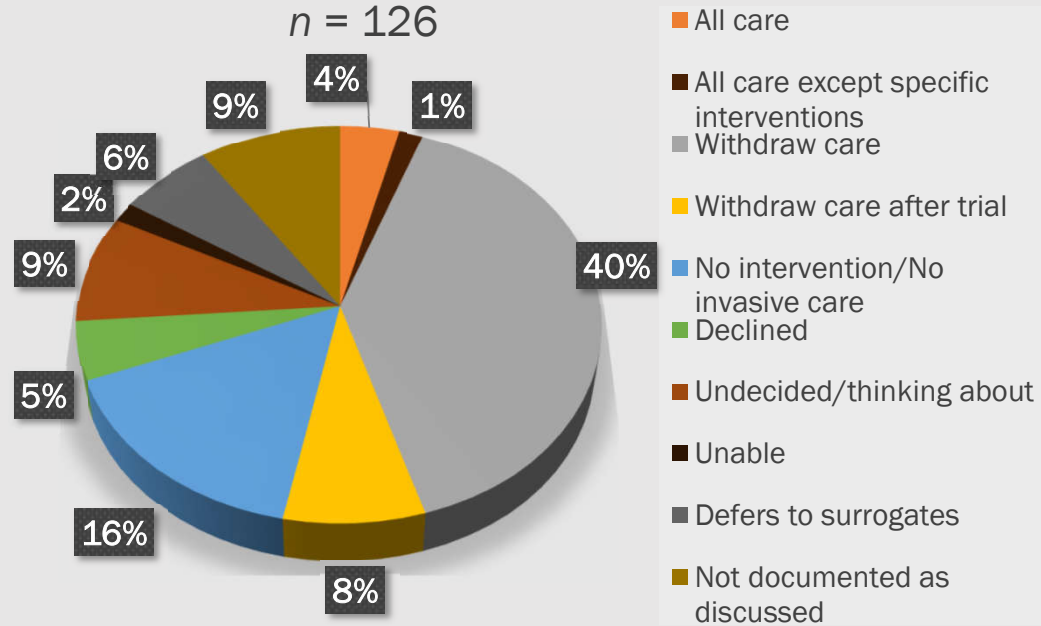
### Code status, if good chance of recovery

n = 126



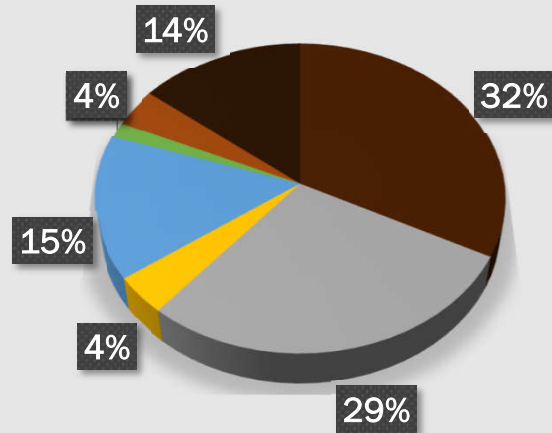
### In event of irreversible brain damage

n = 126



### Care of the body after death

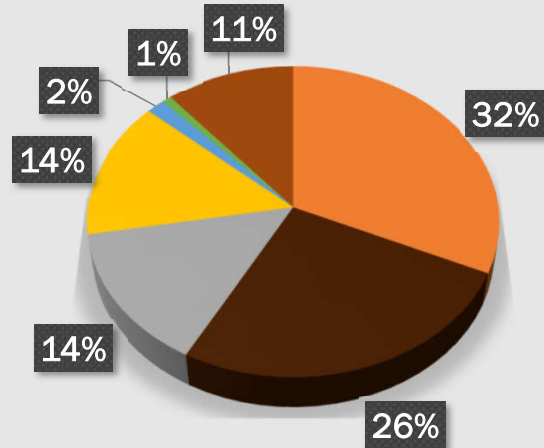
n = 126



- Burial
- Cremation
- Declined
- Undecided/thinking about
- Unable
- Defers to surrogate
- Not documented as discussed

### Organ donations wishes

n = 126



- Yes
- No
- Declined
- Undecided/thinking about
- Unable
- Defers to surrogate
- Not documented as discussed

	Norris 2005	Song 2010	Leung 2014	IFH 2017
Advance Care Planning Discussed	<i>n</i> = 229	<i>n</i> = 70	<i>n</i> = 103	<i>n</i> = 139
Participation Rate	76%	27%	50%	42%
Family/friend as health care proxy	65%	87%	61%	55%
Critical care if in current health/ reasonable chance of recovery	60-89%	49%-yes 29%- defer to surrogate 21%- other/blank	94%	60%
Critical care if in permanent coma	23-31%	9%- yes 19%- other/blank	36%	7% yes 23% not discussed/unsure
City	Seattle	Minneapolis	Toronto	New York
Type of Study	Cross-sectional survey	RCT	Cohort study	Retrospective chart review

# 4. Conclusions & Next Steps

# Take home points

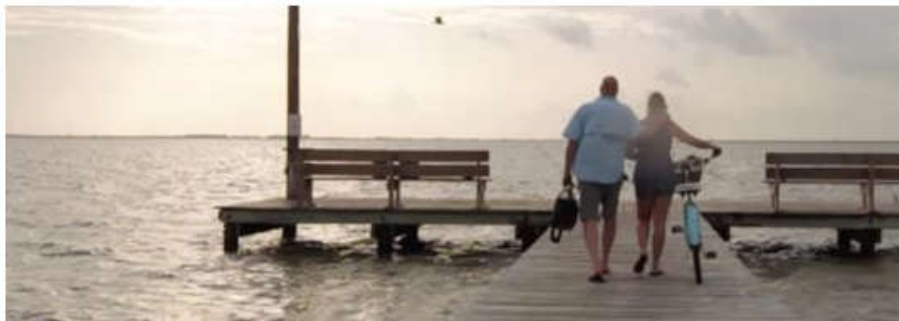
- 1<sup>st</sup> study to establish feasibility of discussing advance care planning in clinical practice in homeless healthcare
- Over 1/3 of patients were surrogateless
- No significant demographic differences were found between patients with surrogates and the surrogateless
- Homeless team staff members can serve as health care proxies to reduce the surrogateless rate

\*\*We need more research to better understand advance care planning and the prevalence of surrogateless in the homeless population\*\*

# Tips for discussions with patients



- Normalize the conversation
- Divide discussions over multiple visits
- Work as a multidisciplinary team
- Use wallet cards
- Identify 1 patient per day for conversations
- Complete documentation correctly
- Identify appropriate documents for your state
- Emphasize choosing a surrogate who will follow your wishes- does not have to be next of kin



[Advance Care Planning](#) > [Advance Directives](#)

### Advance Directives

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<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>



# Reducing the size of the unbefriended/surrogateless population



- Individual volunteer advocate programs
  - External committees of trained volunteers
  - Partner nursing home staff with patients
  - Nonprofits build relationships with patients and serve as “conservators” in the future
- \*Discuss & document health care proxies and advance directives**
- \*Homeless healthcare team members can serve as healthcare proxies**

# Ensuring documents are transmitted to the hospital

- Health care proxy wallet cards
- Sending documents to local hospitals prior to illness
- Improve EHR interoperability
- Include advance care planning documents in RHIOs
- Expand advance care directive registries
  - ❖ eMOLST/ePOLST registries should include all patients & documents

A screenshot of the eMOLST login page. The header is pink with the text "MOLST MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT A POLST Paradigm Program". Below this is a pink bar with "WELCOME TO eMOLST". The main content area is white and contains the text "Please enter your username and password." followed by two input fields: "User name:" and "Password:". At the bottom, there is a "Log On" button and two links: "Forgot password?" and "Need an account?".

<https://www.nysemolstregistry.com>



"I'm afraid I still have more questions than answers."

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