My Choices; Supporting homeless people to complete an advanced statement: Findings from MSc Health Improvement Project

Joanna Cartwright and Alice Edwards

Why

- We had to do a Health Improvement Project for our MSc – Jo in 2017 and Alice in 2018
- Jo had an interest in health inclusion as well as in end of life care from previous job at Compassion in Dying
- Alice had developed an interest in health inequalities and palliative care whilst training as a Nurse and working in Oncology and Haematology.

What

- We felt that with more choice, control and shared decision-making at the end-of-life, patients and loved ones experience a ‘better death’.
- Improving end-of-life care is an NHS ambition - variation in quality of care at the end of life depends on: age, gender identity, sexual orientation, disability, diagnosis and their social circumstances.
- Access to health care often demonstrates the inverse care law; in areas where the requirements are greatest, there is the poorest provision.
- In comparison to the general population homeless people are at higher risk of life-threatening illness, experience premature mortality and are more likely to suffer from tri-morbidity; physical health issues, mental health problems and drug and/or alcohol dependence.
- Homelessness in the East of England rose by 44% between 2015 and 2016, with Norwich seeing a 163% rise in rough sleeping in that time period – and continues to increase.

- City Reach, based in Norwich, are a specialist homeless healthcare provider who had at the time of the audit ‘669 patients registered, 458 of these are classed as being homeless’.
- One theme that emerged from the literature regarding homeless people’s preferences for end-of-life care is their desire for making their wishes known, particularly through written means such as advanced care planning.
- Systematic reviews have concluded that advanced care planning and advanced statements can improve end-of-life care in the general population, and advanced statements could be particularly important for homeless people due to their poorer health trajectories and often nomadic lives.
- Led me to the simplified and specific end of life choices form.

Design

In order to understand how homeless people were living and dying in Norwich, those with lived experience and the staff supporting them were approached for their insight. The patient participation group (PPG) at City Reach attended an informal focus group where they talked about their experiences of their peers dying, as well as their wishes for their own end-of-life. Individuals who support homeless people, such as hostel managers and GPs, were also asked to participate in a survey in order for us to better understand the current situation.

Image from https://medium.muz.li/how-to-conduct-a-focus-group-d401ab7081eb

- The results found that people felt that homeless and marginalised people didn’t die well or occasionally died well; everyone felt that this could be improved (*Figure 1*).
- Most felt that few or no homeless people were able to make choices about their end-of-life and all of those to whom it applied felt that having greater end-of-life choice improves the dying experience (*Figure 2*).
- All those who provided feedback supported the introduction of a form which would seek to ascertain an individual’s wishes for their end-of-life care.

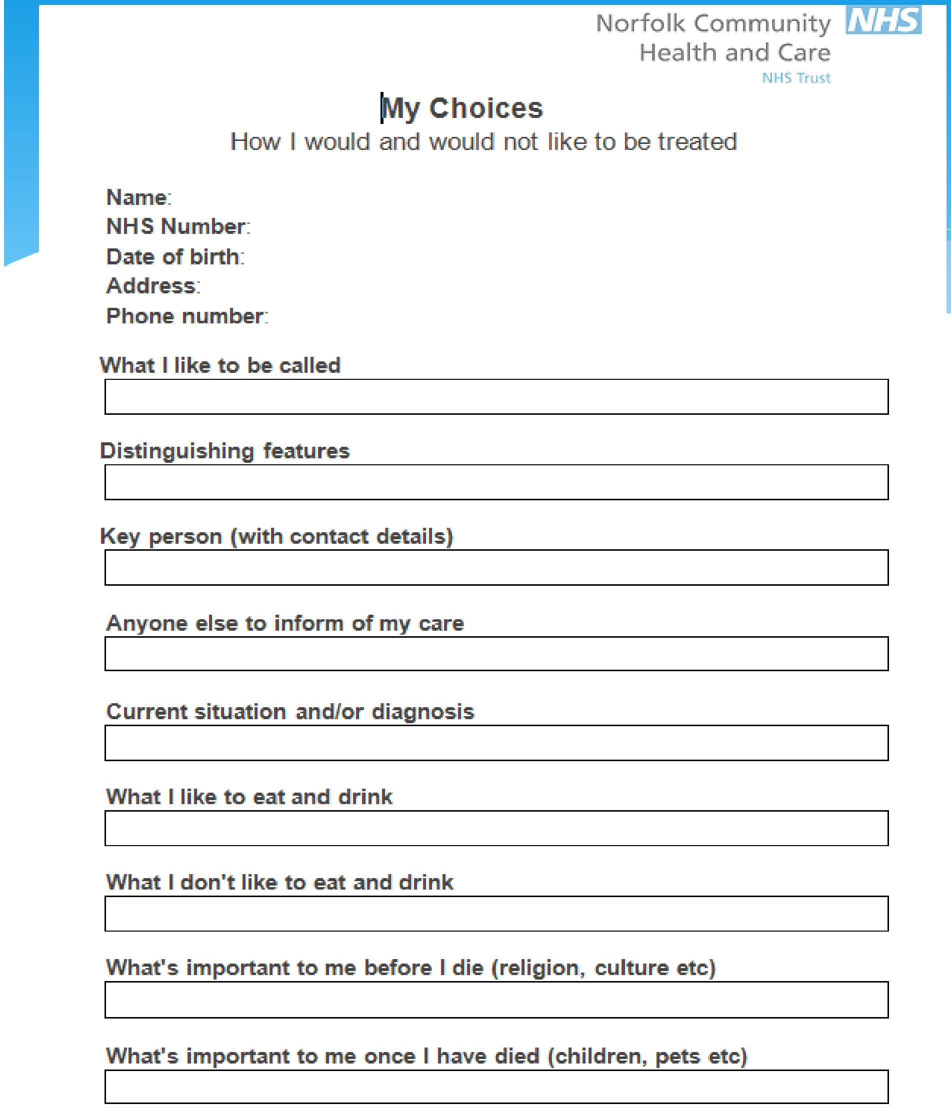
Do homeless people in Norwich currently die well?

Do you feel homeless people in Norwich are supported to make choices about their own care and treatment?

Barriers and existing tools

- Potential barriers were identified including;
  - access to the form and support,
  - timing of the difficult conversations around end-of-life choices,
  - fear of facing up to mortality,
  - and past negative experiences impacting on how homeless and marginalised people view healthcare professionals.
- Various tools exist to allow people to set out their end-of-life choices from charities such as Compassion in Dying , Age UK and the National Council for Palliative Care , but none were wholly appropriate for homeless people, either being too long, too complicated or including choices that weren't relevant and excluding those that were. As a result, the form was designed by taking the most appropriate parts from the Six Steps paperwork, Compassion in Dying's Advance Decision and questions deemed to be important by the PPG.
- The resulting form was discussed and piloted
- The form was received positively, it was commented that as the form was simple and jargon-free

Nb. While this form focuses on end-of-life, many of the questions are relevant to people at any stage in their life and could be offered more broadly to those patients who might benefit from considering their situation and how it might impact how they die, as well as patients who would gain some peace of mind from it.



Norfolk Community Health and Care NHS Trust

My Choices

How I would and would not like to be treated

Name:
NHS Number:
Date of birth:
Address:
Phone number:

What I like to be called

Distinguishing features

Key person (with contact details)

Anyone else to inform of my care

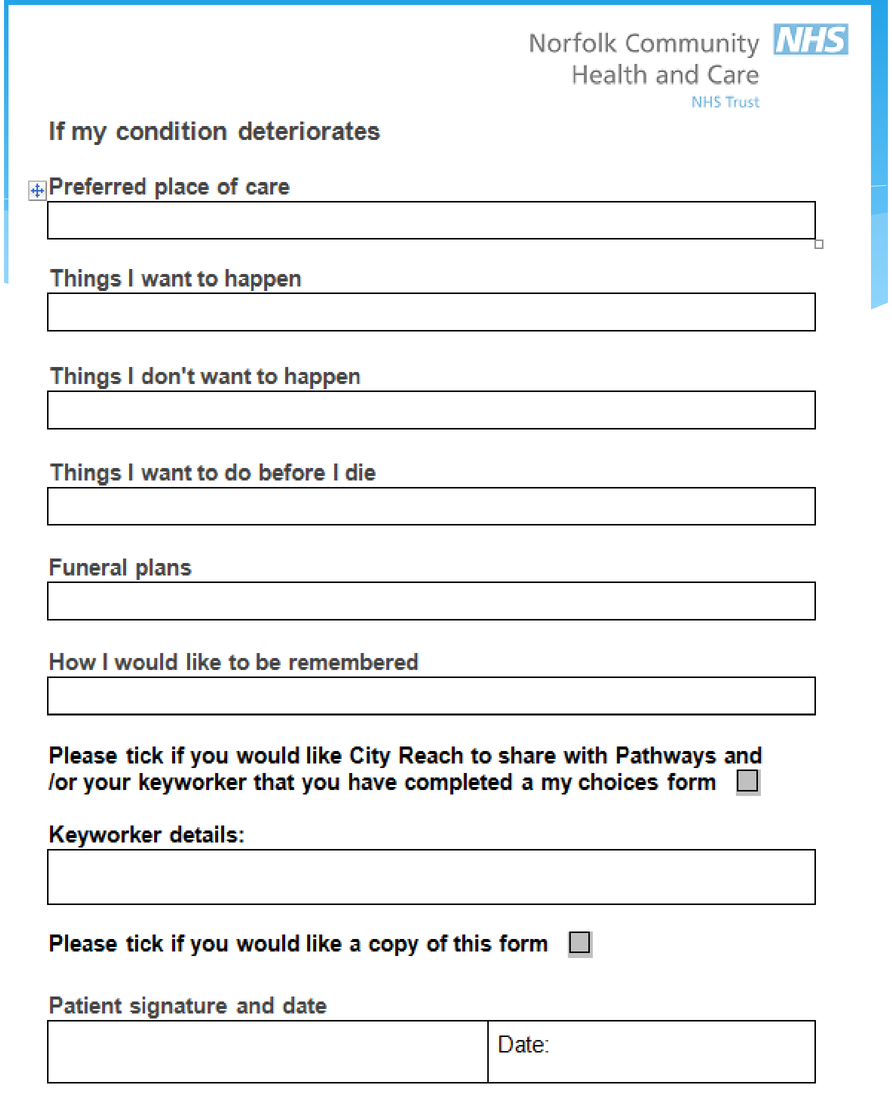
Current situation and/or diagnosis

What I like to eat and drink

What I don't like to eat and drink

What's important to me before I die (religion, culture etc)

What's important to me once I have died (children, pets etc)



Norfolk Community Health and Care NHS Trust

If my condition deteriorates

Preferred place of care

Things I want to happen

Things I don't want to happen

Things I want to do before I die

Funeral plans

How I would like to be remembered

Please tick if you would like City Reach to share with Pathways and /or your keyworker that you have completed a my choices form ☐

Keyworker details:

Please tick if you would like a copy of this form ☐

Patient signature and date

	Date:

Pilot responses

- ***Current situation and/or diagnosis:***

“depression, anxiety, paranoia and insomnia”
“housed nearing end of recovery”
“Epilepsy. Alcohol user. Drug user”

- ***What I like to eat and drink:***

“pasta, potatoes, veg, chicken, beef, home-cooking, soup, home grown produce”
“lots of fish, veg and meats, I enjoy risottos. Non-drinker, I drink mostly tea”
“spaghetti bolognaise. Special brew and wine”

- ***What I don’t like to eat and drink:***

“mashed potato. Cheap cider”
“frozen foods/processed foods. I hate alcohol”
“fish, seafood, hard alcohol”

- ***What is important to me before I die:***

“seeing my little girl grow up. Showing her the correct way to act and behave”

- ***What is important to me once I have died:***

“my daughters care is top priority, anything else doesn’t matter”
“nothing”

- ***Preferred place of care:***

“home, I don’t wish to go into hospital”
“most appropriate”
“never thought about it”

- ***Things I want to happen:***

“make things easy for me without having to be passed around lots of different people”
“organ donation and remains donated to medical science”
“family contacted or informed, no service, just dispose of the remains”

- ***Things I don’t want to happen:***

“I don’t want my daughter to suffer, I don’t want 100 people knowing my case”

- ***Things I want to do before I die:***

“find love and settle down possibly”
“See Liverpool FC play”
”Live a little longer”

- ***Funeral plans:***

“after medical science and donations, cremated”
“burn me and scatter me, I don’t want to be buried or kept in an urn”
“no plans yet, it’s a long way off”

- ***How I would like to be remembered:***

“a passionate head chef who loved his daughter to bits.”
“An ex-army man who always put others before himself”
“prefer to be forgotten. Move on”
“with a big smile”

Six months later

Project Reviewed

Methods

- Project Review
- My Choices Implementation
  - *Would you be surprised if this person were to die in the next 6-12 months?*

Project Review

Benefits

- Supporting patients
- Encouraged reflective practice

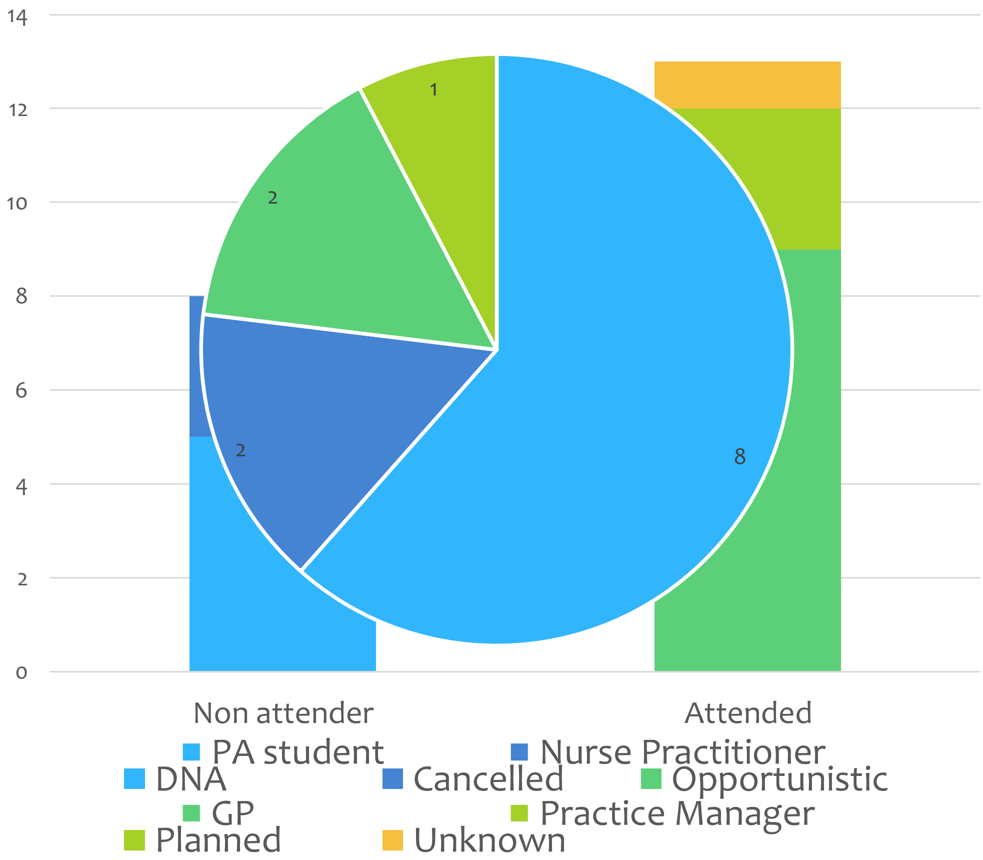
Barriers Encountered:

- Lack of time
- Lack of resources
- Difficulty broaching sensitive topics

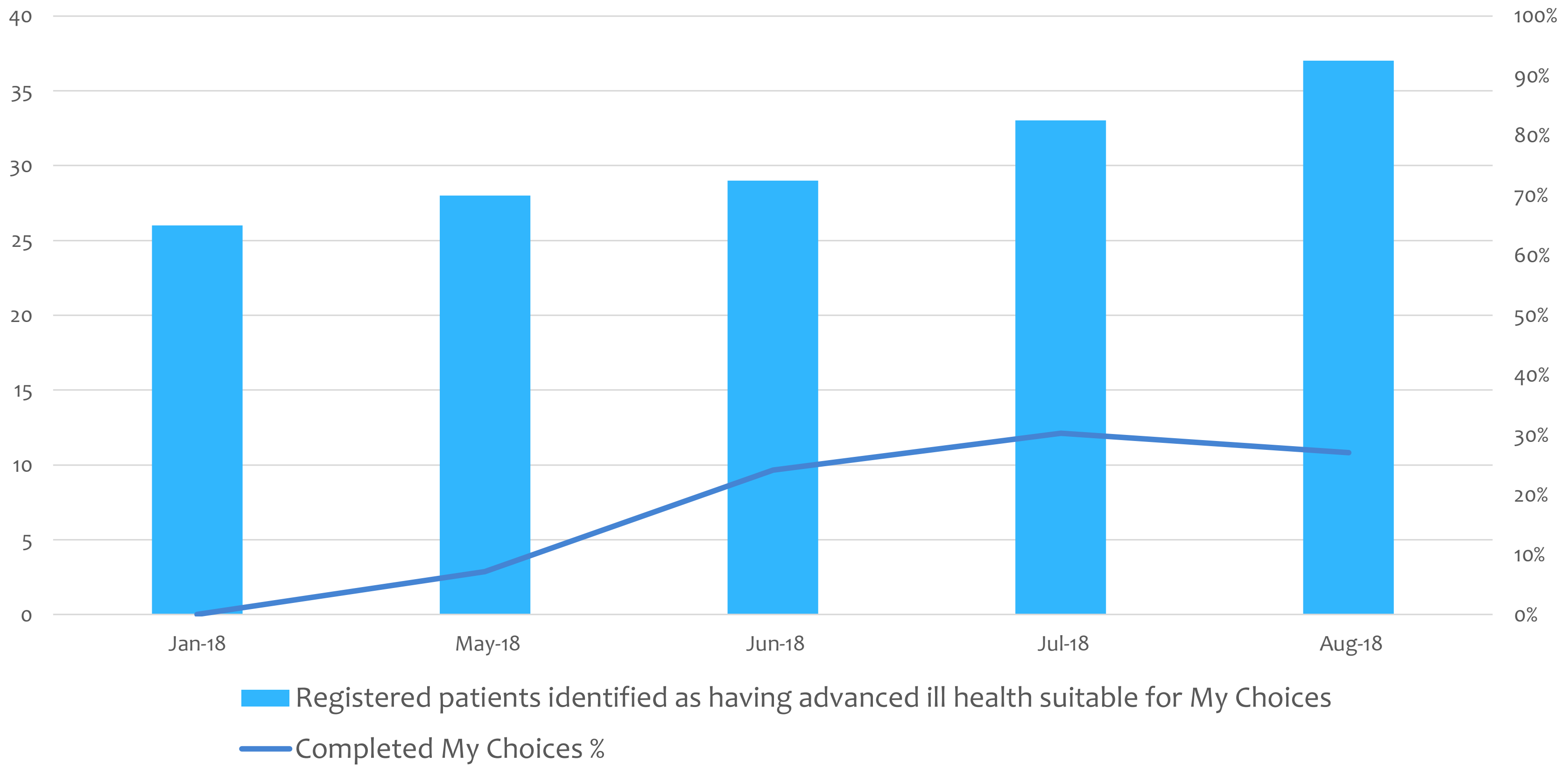
Nvivo word frequency query: All comments from survey respondents

My Choices

- 52 individuals considered for the intervention.
- Median age was 42
- 77% were male.
- Almost 2/3 suffered from tri-morbidity.
- Most forms completed opportunistically.
- My choices forms were completed with the support of a member of the City Reach staff or the PA-S.



My Choices


40
35
30
25
20
15
10
5
0
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Jan-18
May-18
Jun-18
Jul-18
Aug-18
Registered patients identified as having advanced ill health suitable for My Choices
Completed My Choices %

Case Study

Final Thoughts – Feedback from Clinicians about the My Choices Project

It has been a very valuable addition to our service via focusing on our most vulnerable patients and giving them a voice. It is designed in a person centred way and highlights a gap we are keen to address. We are hoping to fully implement this project into our clinical work.

It has been a good opportunity to look at these issues with our patients

Very worthwhile exercise

It has been very worthwhile and evidenced that there is a need for us to understand our patients' choices when they may be chaotic and at risk of death. It is important these are sensitively and appropriately recorded on clinical systems. It has been clear that we have underestimated the clinical time and resource that it requires to do this well and effectively. It is complex in itself both for our patients and staff and we do need a process and system in place to take My choices forward that has the appropriate clinical governance and quality standards in place.