THE NATIONAL END OF LIFE CARE AUDIT AND REVIEW SYSTEM

Some findings relevant to dementia

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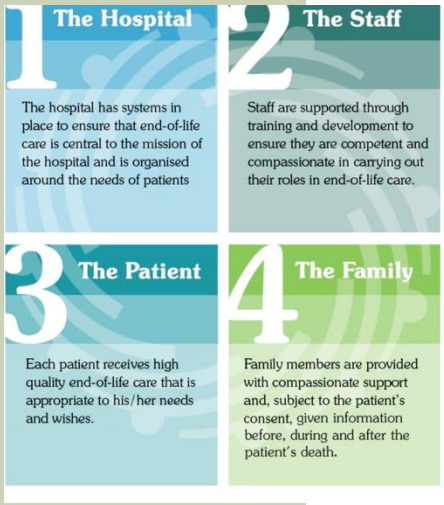
Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

The ATLANTIC Philanthropies

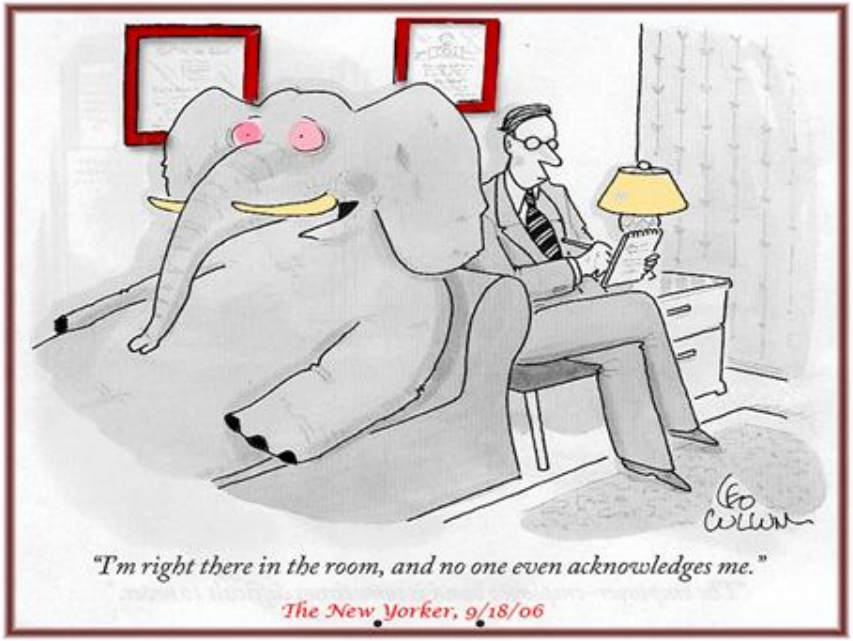
BACKGROUND

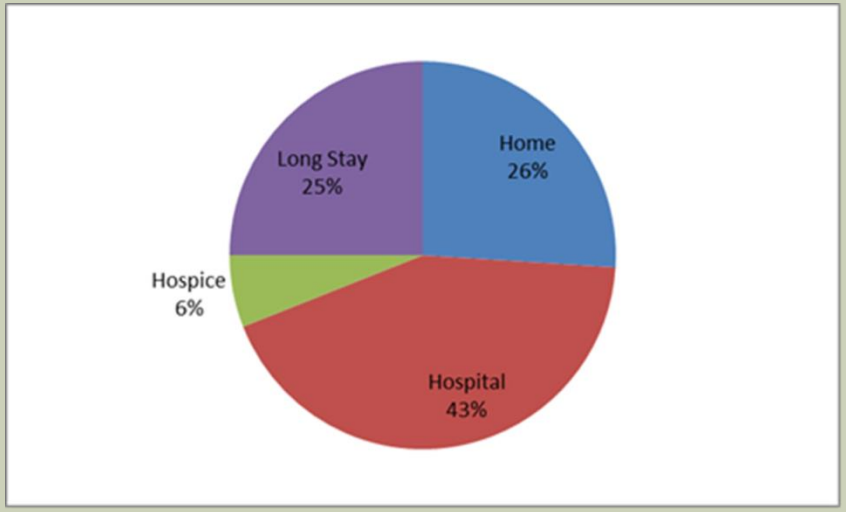
- In 2011 a Project Advisory Group was established to advise and support the development of a National End of Life Care Audit and Review System.
- The system was piloted in 2012/2013 and has been used by healthcare staff to review the deaths of more than 140 people in Ireland, in all settings where people die (i.e. acute hospitals, residential care services, hospices and home).
- The system enables staff and bereaved relatives to review and reflect upon end of life care across eight, evidence based domains.



AIM

- The aim of the pilot was to test the audit and review system, with a view to documenting the pilot process and experiences and identifying emerging issues to be considered in advance of national implementation.





MIXED METHOD APPROACH

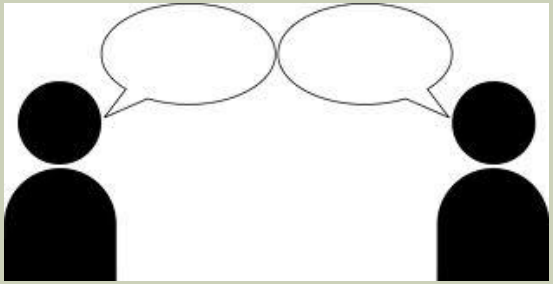
- Comparison of data from 130 staff reviews, 59 bereaved relatives and 23 independent assessments of care;
- Observation of audit and review meetings with staff;
- Questionnaires examining the experience of audit facilitators;
- Cognitive testing of the tools with healthcare staff using the QAS;
- Focus groups and one-to-one interviews with audit managers and facilitators.

EXPERIENCE


I might be a work in progress but every day, I get a little bit wiser, a little bit better, a little bit stronger.
MORE FROM ILIKETO

57% patients died in a single room

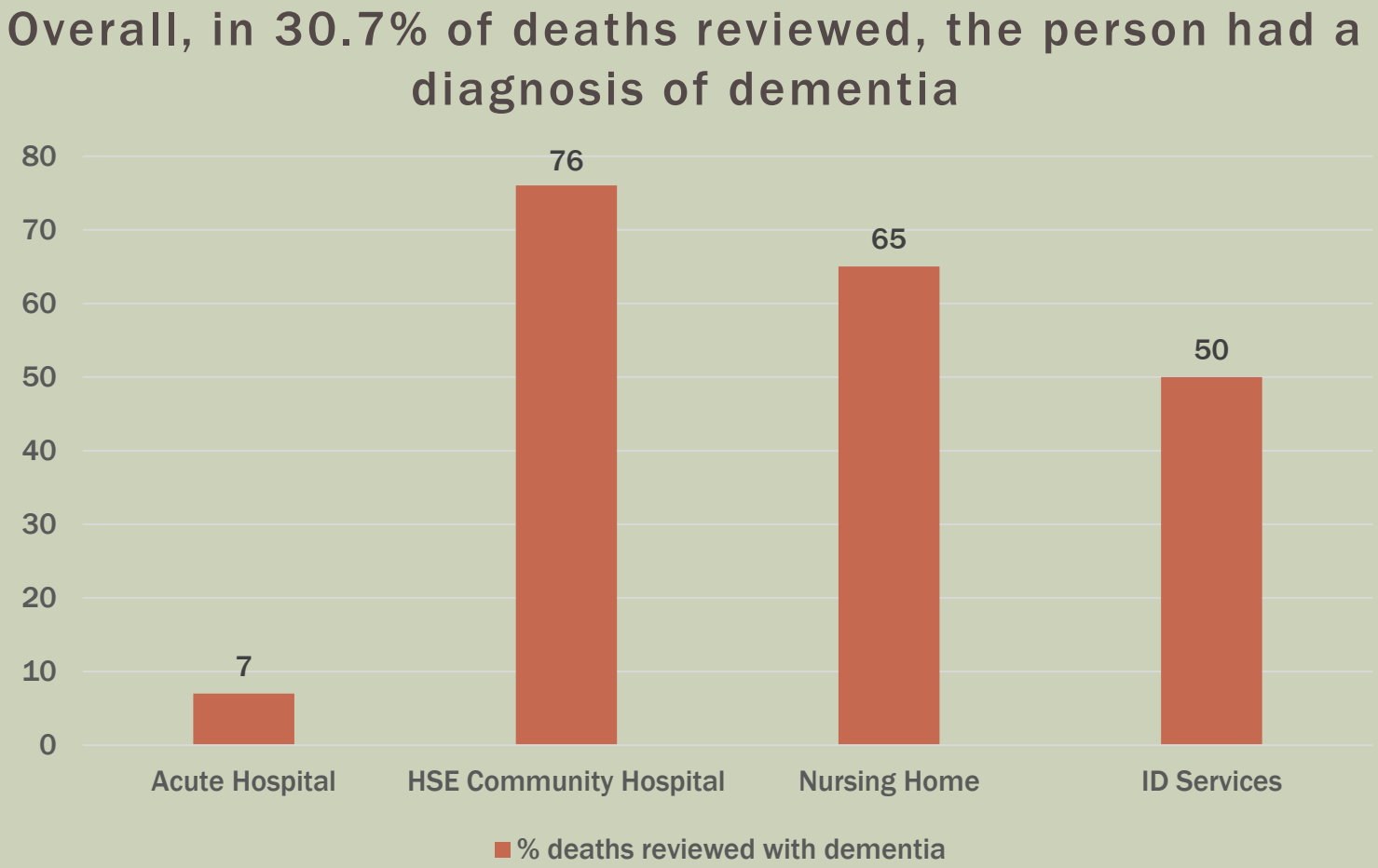
84% of patients were in at least some pain during the last week of life.
In most cases staff and relatives considered it quite well managed (8/10)



76% of healthcare staff said that they didn't discuss end of life care preferences with the person. In 81% of cases it's discussed with the family.

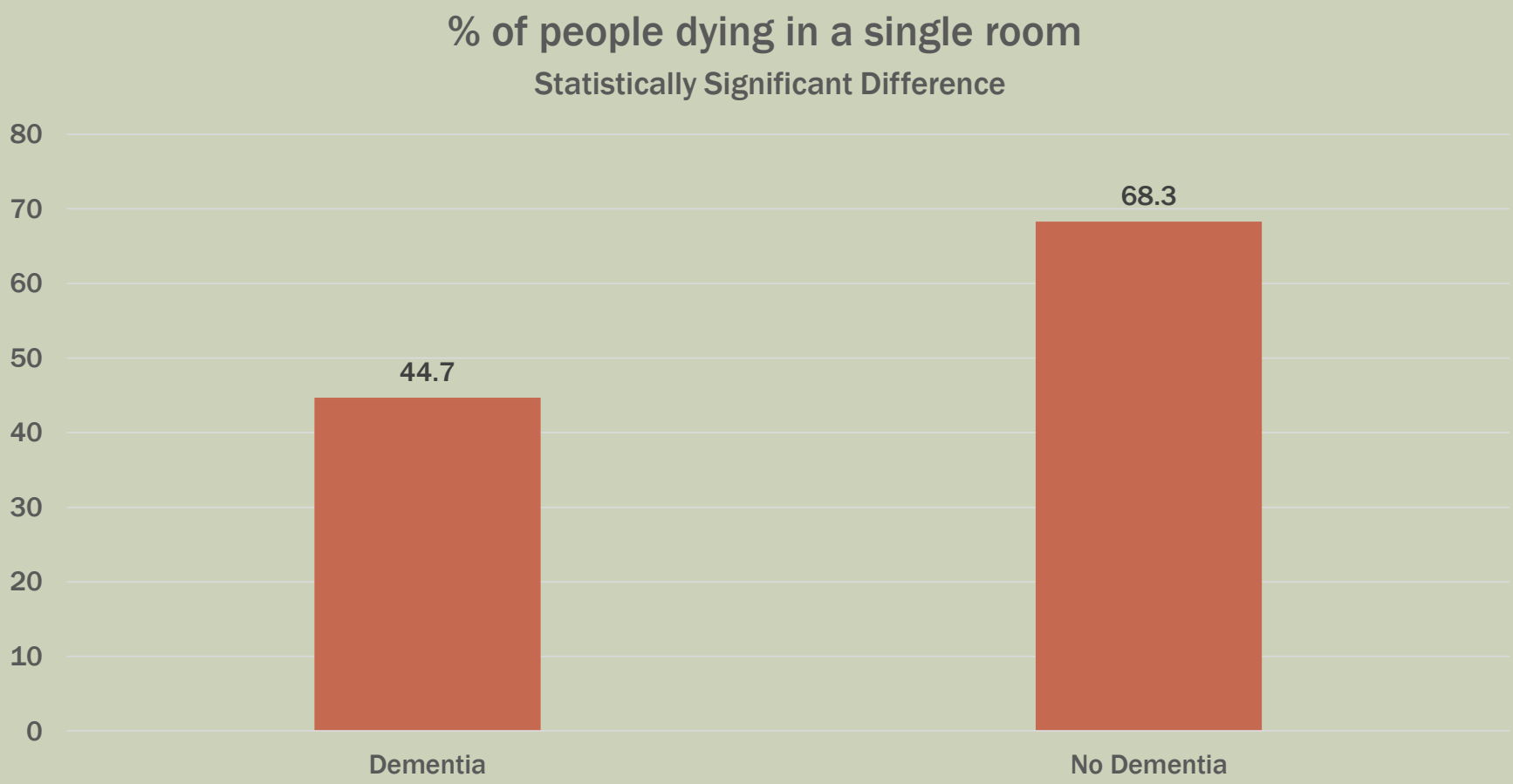
Specialist palliative care were involved in the care of 27% deaths. Not everyone needs SPC but on review staff identified 20.3% who could have benefited from SPC.

SO…HOW MANY PEOPLE HAD DEMENTIA?

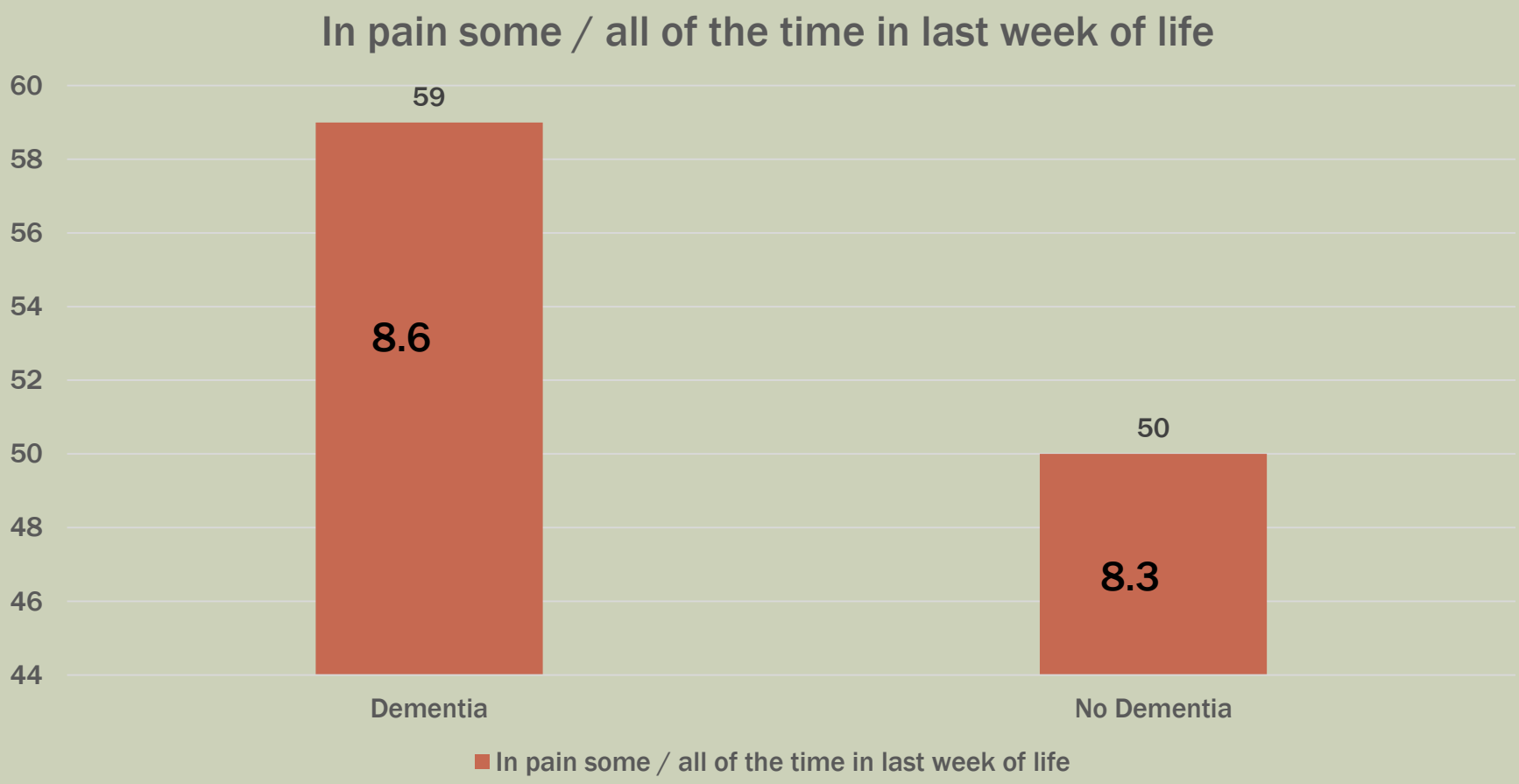


So,
does it make a difference if you have dementia?

YOU MIGHT BE LESS LIKELY TO DIE IN A SINGLE ROOM…



YOU MIGHT BE A LITTLE BIT MORE LIKELY TO BE IN PAIN BUT IT MIGHT BE BETTER MANAGED



YOU PROBABLY HAVEN'T DISCUSSED YOUR EOLC PREFERENCES PERSONALLY

YOU MIGHT BE LESS LIKELY TO BE REFERRED TO SPECIALIST PALLIATIVE CARE

23% of people with dementia were referred to SPC

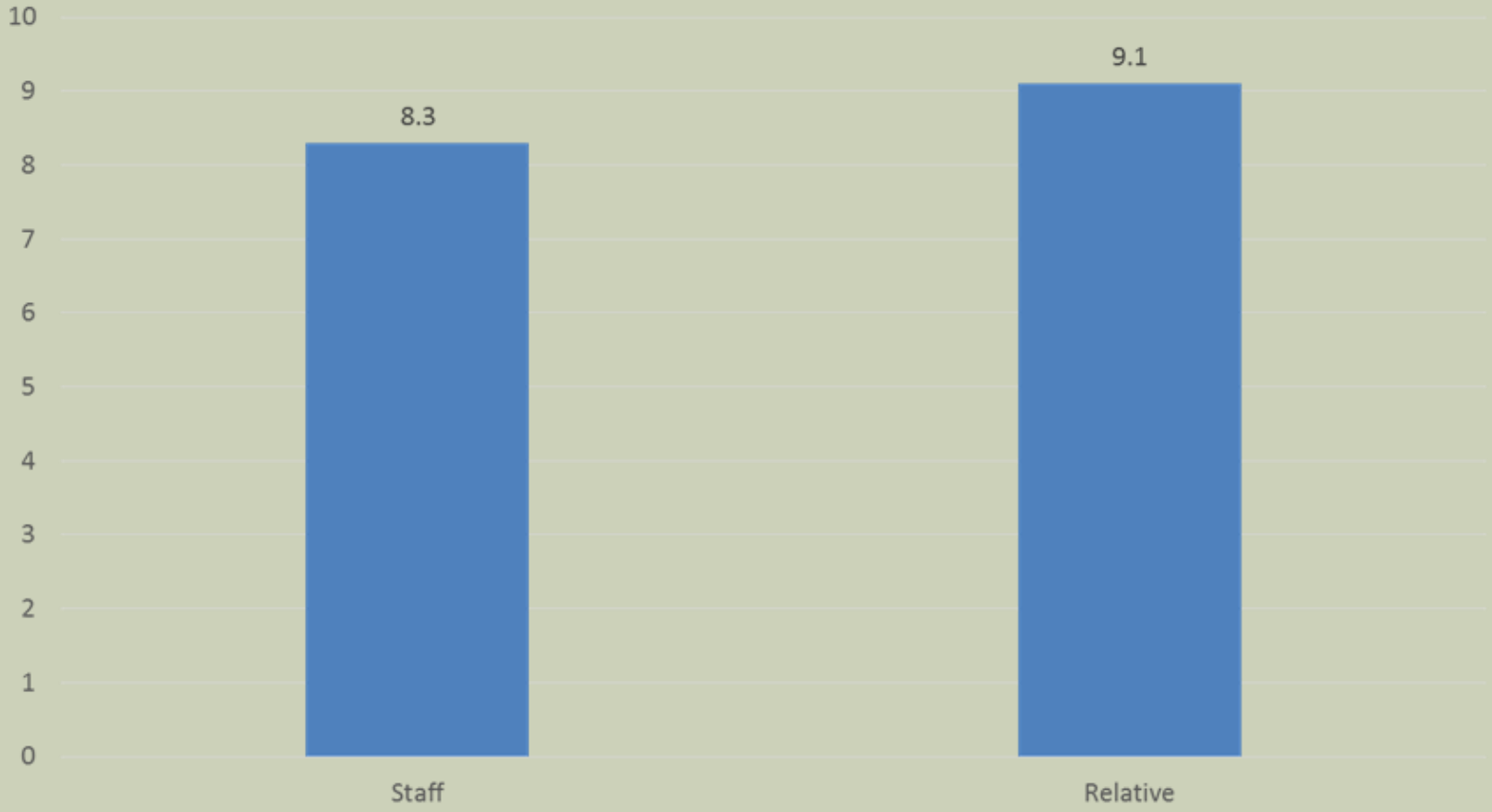
49% of people with no dementia were referred to SPC

In hindsight 19% of those with dementia not referred would have benefited

In hindsight 26% of those with dementia not referred would have benefited

OVERALL…IMAGINE THIS PERSON WAS YOU?

WOULD IT BE ACCEPTABLE TO BE CARED FOR IN THIS WAY IN THE LAST WEEK OF LIFE?



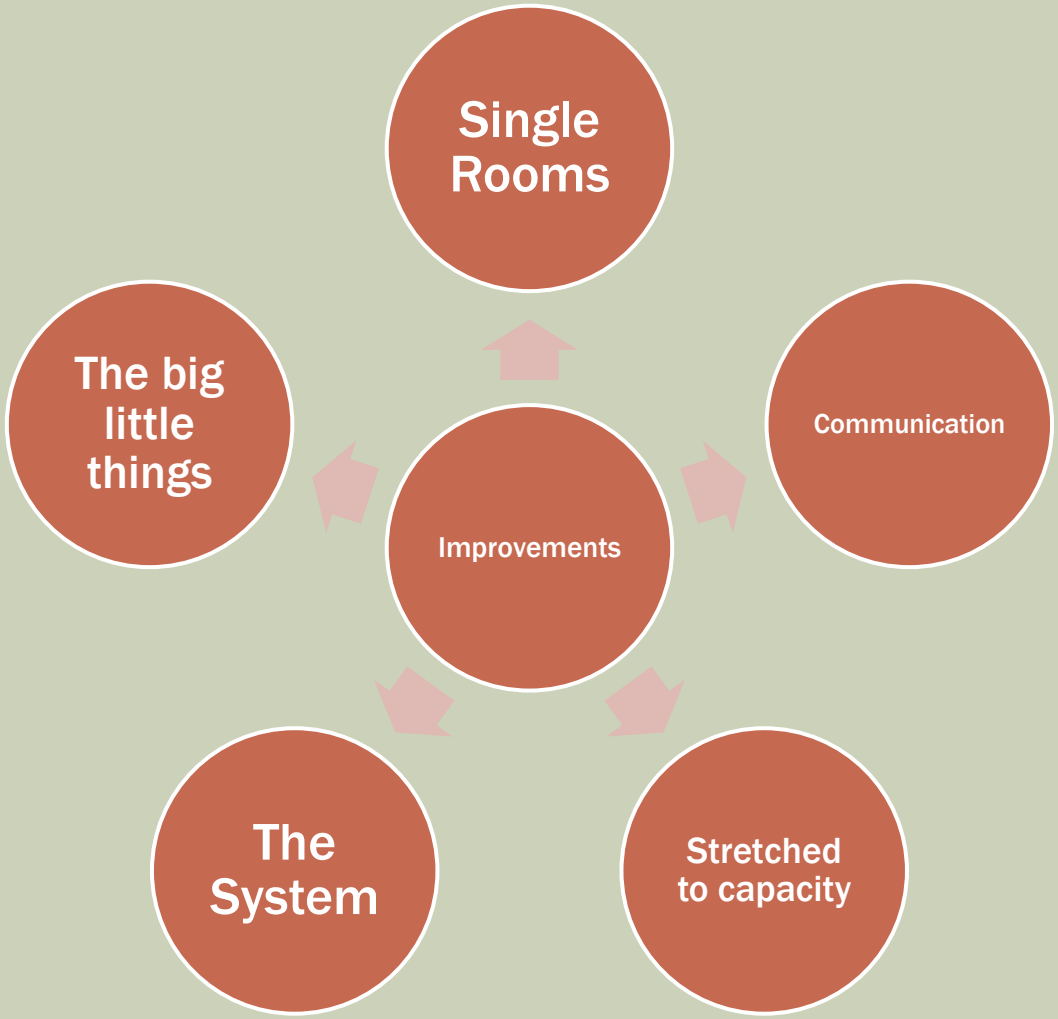
QUALITATIVE FINDINGS…*MOST* PEOPLE ARE SATISFIED

"Just keep doing what you are doing - the care and attention received was excellent, considered, respectful and dignified.

IMPORTANT ISSUES FOR PRIMARY CARE

- Initiating discussions
- Supporting those who want to engage
- Display resources
- Honesty
- Assessment of capacity
- Agreeing status re: DNAR etc
- Electronic communication
- OOH Services
- Listen to family and patient
- Look after yourself

1 IN 4 RELATIVES OFFERED SUGGESTIONS FOR IMPROVEMENT…



WE'RE HAPPY

From mine and my family's experience with our relatives death we were impressed and very happy with staff. It is important to state that we had built up a very good relationship with all staff over the years while our relative was in the nursing home. She received great care throughout and also while she was dying RIP.

Just keep doing what you are doing - the care and attention received was excellent, considered, respectful and dignified.

There are always ways of improving, but we the family, were pleased our father died with dignity and respect and are grateful to the people who cared for him.

THERE ARE AREAS FOR IMPROVEMENT…

One of the doctors could have been more sensitive answering questions especially when my wife was dying, more training might help.

Insufficient bathroom facilities to care for patients. Fortunately, their needs were met by the most caring staff. I bless them daily.

When staff know their patient is dying a pain management team and palliative care team should be provided without family having to demand it. And this should be discussed with the family as early as possible so a plan of action is already in place (where possible). Also a survey from the nursing home for family to fill in might also help them identify areas which needs attention.

Check hospital re: medications as mistakes were made. Take more heed to patient and family as regards needs. More control of medication and feeding. Waited for feeding cup for my dad for 6 weeks and he still did not get it. Would be nice to have a place of rest and not have to go to funeral home so staff family and friends could visit. Staff were brilliant at the end.

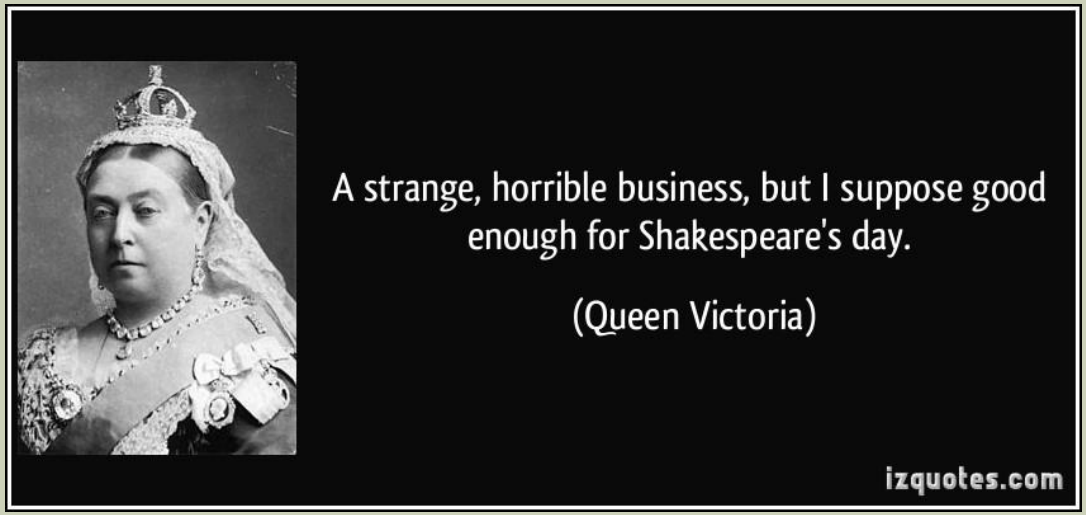
The nurses were all very willing to help, but there were too many residents for the size of the nursing home.

She shared a room and the other occupant refused to leave her bed as she was ill. This caused a lot of difficulty. She herself was not mentally in a position to deal with my mother dying. Hence I believe that a private dying room is a vital necessity for privacy and comfort. The occupant left the room upon my mothers death, so I believe she was upset too.

A 75 YEAR OLD DAUGHTER OF A 102 YEAR OLD WOMAN WHO DIED WITH DEMENTIA…

Staff at x hospital were excellent to my mother but she did not need to be in the hospital most of the 5 months but we could not afford full time care which at nearly 102 years of age any mother then required. I want the HSE to have the fair deal applied to own home as well as nursing homes but although we had fair deal approval my mother died after a chest infection while waiting on a place. I got a call this month from x CNU to say they had a place - 4 months after she had died. I am very upset that my mother had to spend her last days in hospital as she was not very ill but as I was the only carer at 75 years I could not do full time care with an 84 year old husband. However I was grateful for the hospitals care.

DOYLE, 2013



"patient experience is consistently positively associated with patient safety and clinical effectiveness across a wide range of disease areas, study designs, settings, population groups and outcome measures…clinicians should resist side-lining patient experience as too subjective or mood orientated, divorced from "real" clinical work of measuring safety and effectiveness".

TO CONCLUDE

- The system appears to be feasible and recognised as useful, particularly by healthcare teams providing end of life care in hospitals and in residential care settings.
- A modified tool is required to review deaths in the home and hospice.
- Areas were identified where the validity of the tool could be improved through changes in language and the provision of additional definitions.
- Internal consistency of the tool could be improved if consideration is given to a separate tool for the review of sudden deaths.
- The qualitative feedback from bereaved relatives was considered powerful by healthcare staff and is potentially the biggest driver of quality improvement.
- The pilot findings have contributed to the development of v20.0 of the National End of Life Audit and Review System, that is now being tested.

YOU CAN GET INVOLVED…

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REFERENCES & ACKNOWLEDGEMENTS

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Thank you to:

- The Audit and Review Consultative Committee
- The organisations who engaged in the testing of the system
- The staff who gave their time to attend the audit and review meetings
- The audit managers challenged with the task of bringing everyone together
- The relatives who shared their experiences openly