Provision of culturally appropriate end of life care at NBT

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Introduction

- ‘Culture’ is a dynamic system of beliefs, values, lifestyles, and opportunities that provides one with a sense of safety, identity, and meaning of and for life within a social, biologic, physical or political niche.

- Evidence from national audits suggests that the cultural needs of patients are poorly understood and explored.

- This deficit of care can potentially lead to barriers in end-of-life care provision for minority groups that hold vastly different cultural values to western culture.

NACEL AUDIT – NBT results

- Documentation of assessment of both emotional/psychological needs as 28% (National Average 34%) spiritual/ religious needs was at 31% (National Average 36%)

- Care provided to families and others: Only 28% felt they were given enough spiritual, religious or cultural support (National Average 32%)

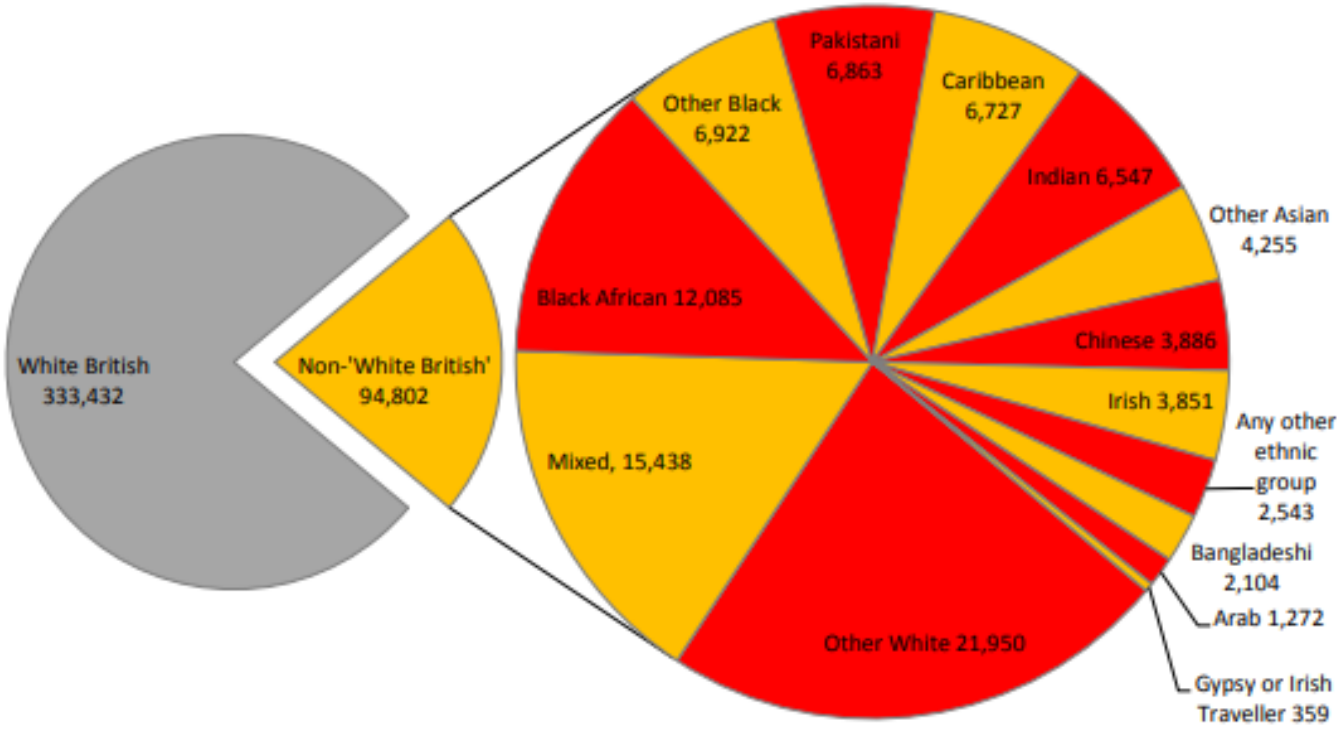
- However, 74% staff felt confident responding to the spiritual, emotional, and cultural needs of those important to the dying person (National Average 72%)

- UK becoming more ethnically diverse, and these groups are growing older.

- Poor access among BAME groups
  - Lack of referrals
  - Lack of awareness of services
  - Bad experiences of healthcare previously (discrimination breeds mistrust)
  - Conflicting family/religious views

- Disparities in care received
  - **Lack of sensitivity to cultural differences and needs**
  - Poor communication
  - Lack of translators
  - Low availability of training for healthcare professionals

Bristol's Demographics – Ethnic Diversity



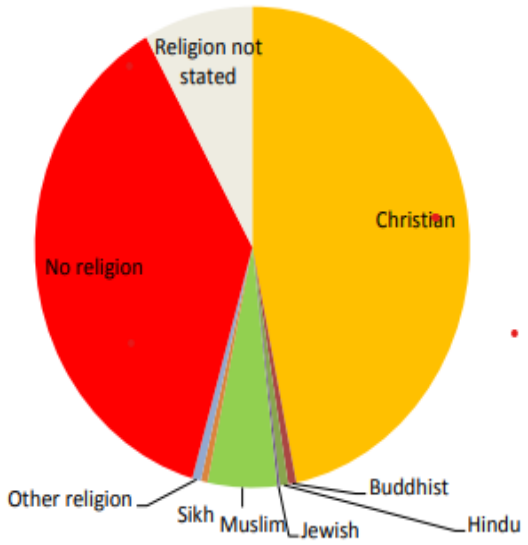
Population by Ethnic Group

Source: 2011 Census Office for National Statistics © Crown Copyright 2012

		Bristol	Bristol %	England & Wales %
	Total population	**428,234**	**100.0**	**100.0**
White	British	333,432	77.9	80.5
	Irish	3,851	0.9	0.9
	Gypsy or Irish Traveller	359	0.1	0.1
	Other White	21,950	5.1	4.4
Mixed/multiple ethnic group	White and Black Caribbean	7,389	1.7	0.8
	White and Black African	1,533	0.4	0.3
	White and Asian	3,402	0.8	0.6
	Other Mixed	3,114	0.7	0.5
Asian/Asian British	Indian	6,547	1.5	2.5
	Pakistani	6,863	1.6	2.0
	Bangladeshi	2,104	0.5	0.8
	Chinese	3,886	0.9	0.7
	Other Asian	4,255	1.0	1.5
Black/African/Caribbean/Black British	African	12,085	2.8	1.8
	Caribbean	6,727	1.6	1.1
	Other Black	6,922	1.6	0.5
Other ethnic group	Arab	1,272	0.3	0.4
	Any other ethnic group	2,543	0.6	0.6
	Total White groups	**359,592**	**84.0**	**86.0**
	Total Black and minority ethnic groups (BME)	**68,642**	**16.0**	**14.0**

Bristol's Demographics- Diversity of Faith

Figure 1: Religion in Bristol
Source: 2011 Census ONS Crown Copyright Reserved [from Nomis on 5 June 2013]



Religion	Number	%
Christian	200,254	46.8
Buddhist	2549	0.6
Hindu	2712	0.6
Jewish	77	0.2
Muslim	22016	5.1
Sikh	2133	0.5
Other Religion	2793	0.7
No Religion	160218	37.4
Religion not stated	34782	8.1

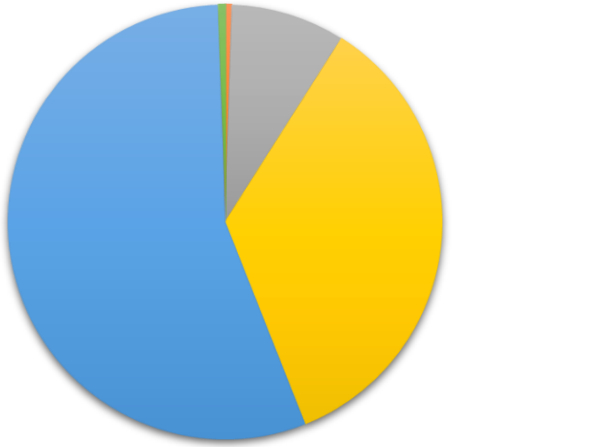
Objectives

- We aimed to conduct a service evaluation of current practice in the North Bristol NHS Trust.
- To evaluate how well we are assessing the religious, cultural and spiritual needs of the patients who die at NBT, in order to guide interventions to improve quality of life and perceived quality of death.

Method

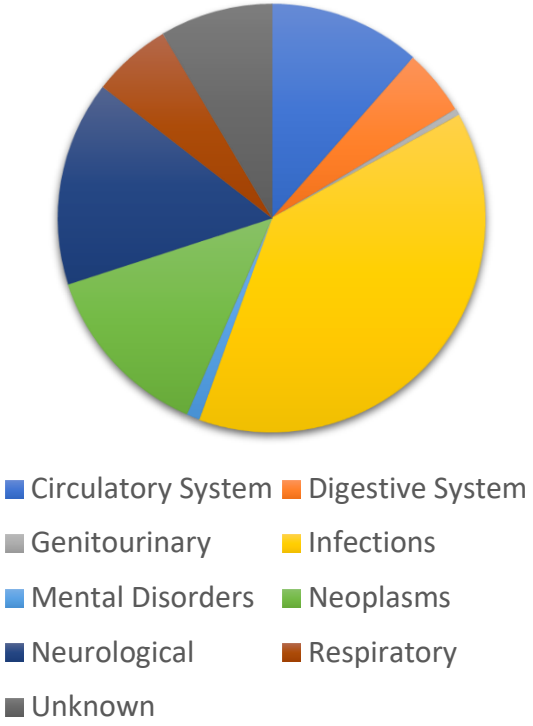
- 200 randomly selected patients who died whilst admitted to NBT between August and October 2021.
- Retrospective case note review to look at documented characteristics such as ethnicity, religion and nationality. Also looked at whether there was any documentation of discussion regarding spiritual/ cultural/ religious requirements at the end of life.
- Also took demographic data and cause of death.

Age Range

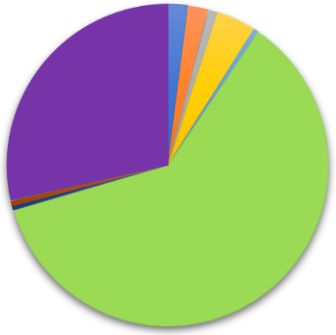


Documented Gender

Cause of Death

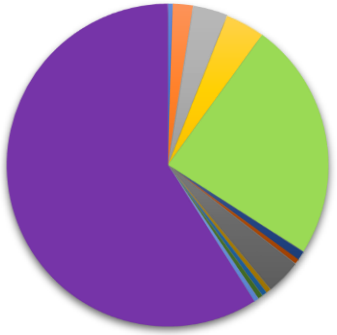


Ethnicity



- Any other Ethnic Group
- Any other White Background
- Black or Black British
- British/ Mixed British
- Caribbean
- White
- Asian or Asian British
- Irish
- Not Documented

Religion

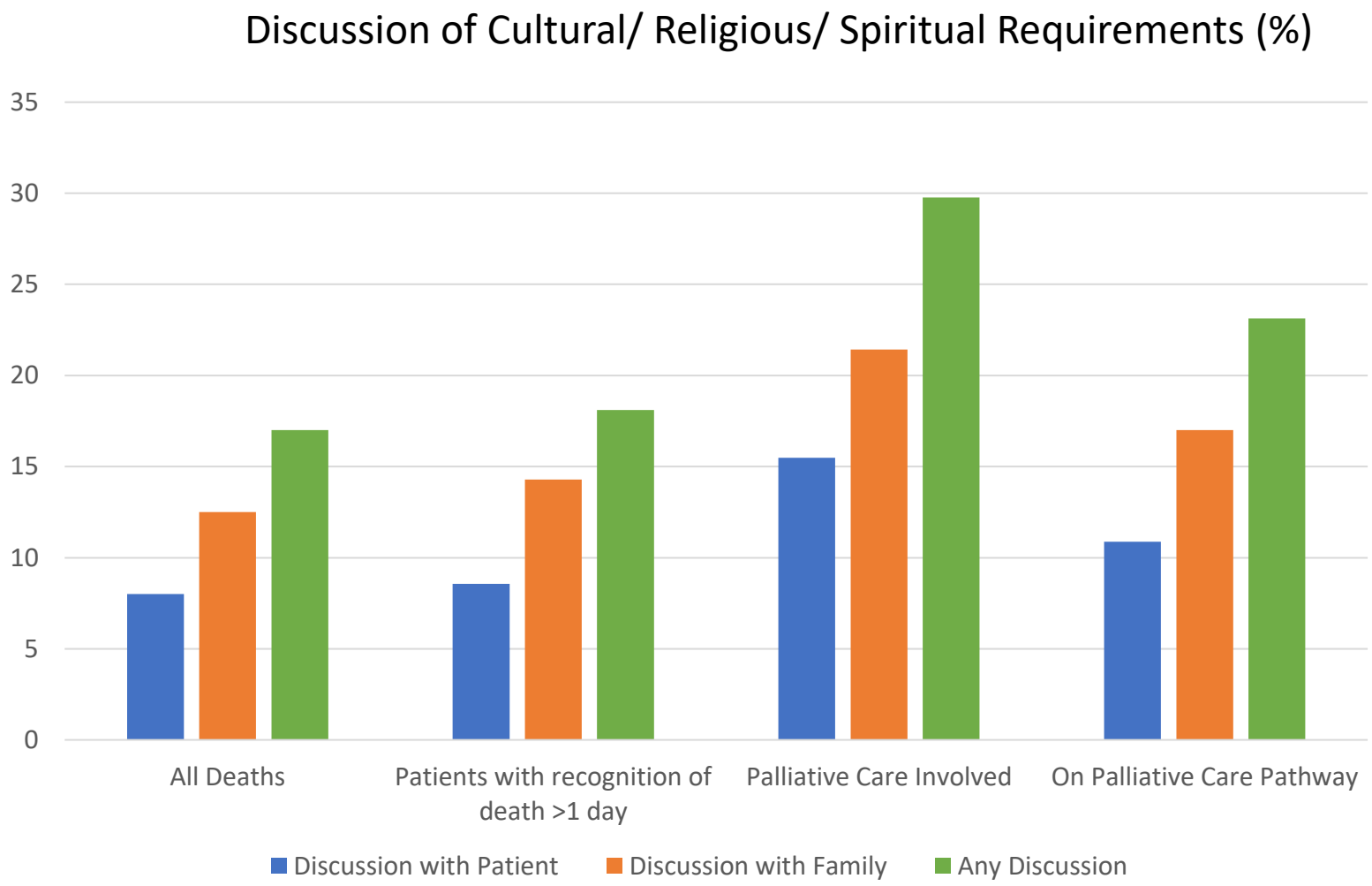


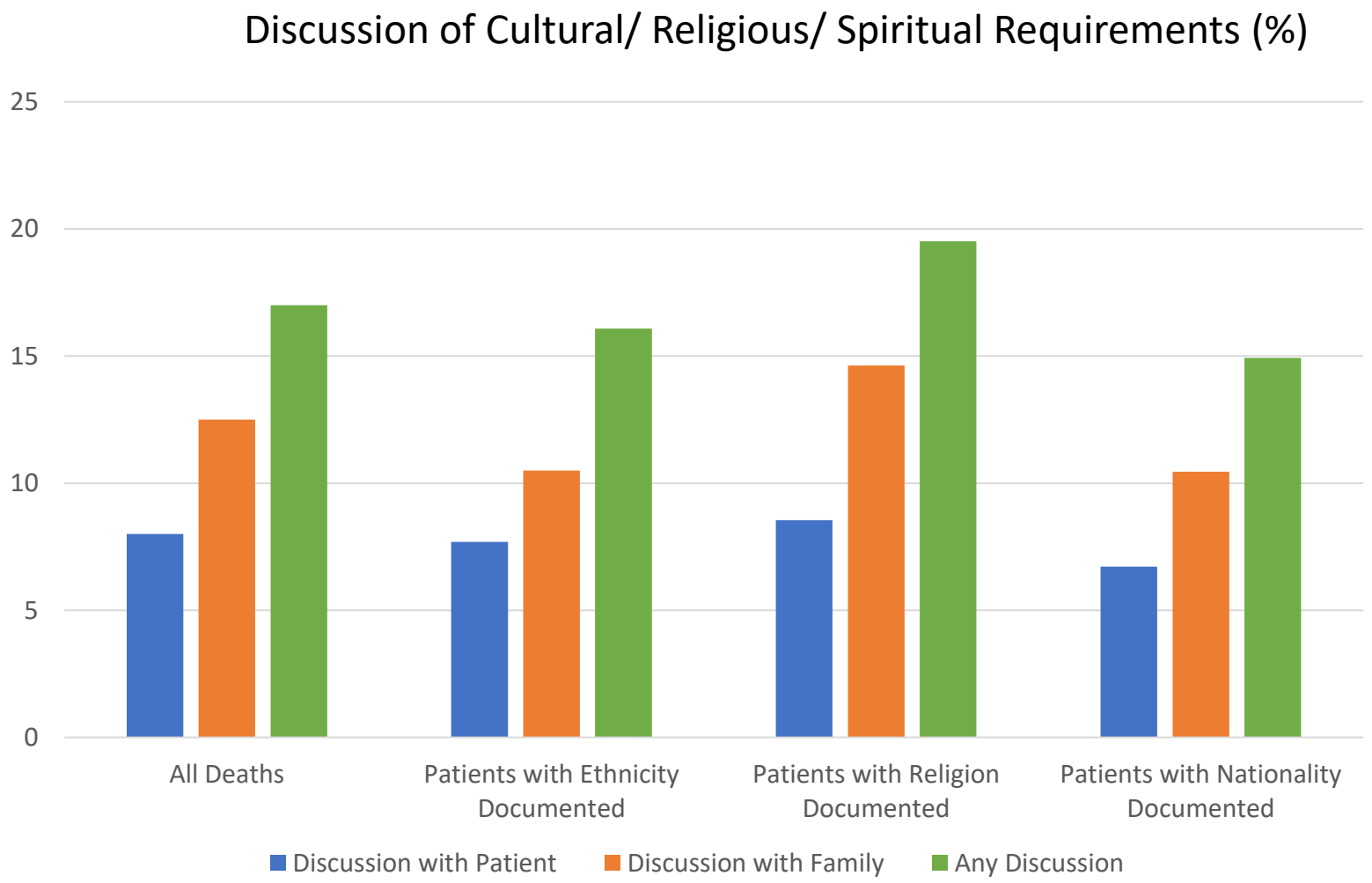
- Athiest
- Baptist
- Catholic
- Christian
- Church of England
- Methodism
- Muslim
- Not Religious
- Other Not Listed
- Pentecostal
- Presbytarian
- Sikhism
- Not Documented

Nationality

- British
- Indian
- Irish
- Not Documented

Percentage Not Documented (%)	
Ethnicity	28.5
Religion	59
Nationality	32


Discussion of Cultural/ Religious/ Spiritual Requirements (%)
35
30
25
20
15
10
5
0
All Deaths
Patients with recognition of death >1 day
Palliative Care Involved
On Palliative Care Pathway
Discussion with Patient
Discussion with Family
Any Discussion


Discussion of Cultural/ Religious/ Spiritual Requirements (%)
25
20
15
10
5
0
All Deaths
Patients with Ethnicity Documented
Patients with Religion Documented
Patients with Nationality Documented
Discussion with Patient
Discussion with Family
Any Discussion

Summary

- There was a deficit in recording of religious **(41%, N=82)** and ethnic data **(71.5%, N=142)** making it difficult to come to conclusions on the diversity of our patient group.
- Cultural preferences at end of life was documented to be discussed with patient for only **8% (N=16)** patients and with the patient's family for only **12.5% (N=25)** patients**.**
- Earlier recognition of the patient dying and recording of the patient's ethnicity and religion on Lorenzo had no impact on the likelihood of these discussions happening.
- There was some improvement in the likelihood of these discussions occurring when patients were seen by the palliative care team but numbers were still low.
- **53%** of patients who were asked if they had any requirements were referred on to the chaplaincy. This implies a significant number of patients who were not asked, would have had requirements we could have addressed.

Discussion

- Providing high quality end of life care requires us to address cultural needs of our patients at end of life.
- This service evaluation indicates that cultural preferences are not discussed consistently in NBT.
- There is also a paucity of recording of ethnic and religious data which could potentially hide disparities in care among different groups.
- There is a possibility in some of the cases these discussions were had but there was no documentation.

Next Steps

- How can we collect meaningful data that improves the care given to patients at end of life?
  - Educating staff and public why collecting such data is important
  - Empowering staff to ask the relevant questions that pertain to end of life care needs

- How do we provide more culturally appropriate at end of life?
  - Having more diversity within the workforce and on boards
  - Learning from communities of what a good death looks like
  - Focused cultural competency and communication skills training

- What do you think?

References

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